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ABSTRACT

Twenty-three papers address issues of access, case management, innovative computer applications, and information and referral in the use of information technology by individuals with disabilities and their families. The papers are: "Improving the Use of Information Technology by Individuals with Disabilities and Their Families" (William H. Graves); "The Struggle Toward a Comprehensive State-Wide Information System" (Robert W. Bass et al.); "Telecommunications Equipment and Services for People with Disabilities" (David Baquis); "AIRS & NSIT - Will the Tail Wag the Dog?" (Charles Juhn); "Organizing Assistive Technology Information Centers" (Marian Hall); "Implementing PL 99-457's Childfind Component With the Help of Electronic Data Manipulation" (Coleman Poses); "Assistive Technology Terms and Concepts" (Janie B. Scott); "Automation of Targeted Care Management" (Deborah H. Coble, Steven Massey); "Development of an Agency-Wide Plan to Establish an Electronic Communication System and Better Integrate Information Technology" (Isaac Joyner, Darold Klauk); "Computer Training for the Health Care Professional" (Alan M. Kaplan et al.); "The South Carolina Commission on Aging: An Automated Statewide System of Case Management for the Elderly of South Carolina" (Matthew Lynch et al.); "An Innovative Approach for the Selection of Children with Severe Emotional Disturbances" (Wendell Price et al.); "Are Applications for a Computer-Based System Designed to Provide Linkages Between the Health Science Center and Remote or Rural Health Care Providers and Health Care Recipients?" (Sherald A. Ramirez, Judith Flagle); "Integrating Information and Referral With Client Tracking Systems" (Jacquelyn Vincson U'Deen, Edward Hamlin); "Tracking System for At-Risk & Disabled Infants: A Model for Service Coordination" (Duvon Winborne); "Computer Technology and Leisure Skills" (Gordon St. Michel, Robert Cunningham); "Using Laser Videodiscs and DVI (Digital Video Interactive) to Develop Visual Databases" (Ronald Thorkildsen); "Systematic Approaches to Data Acquisition and in Information and Referral, or 'What Do You Mean, Expect a 10% Return Rate?'" (Robert W. Bass); "Publicizing Your Information and Referral Program" (Clarice Eichelberger); "Getting the Word Out: Publicizing Your Information and Referral Service" (Duane Gimbel); "Developing Information and Retrieval Software: It's a People Process" (George Jones); "Achieving Consent: Delaware's Integrated Service Information System" (Roseanne Griff-Cabelli); and "Beyond Information and Referral: Are There Other Benefits to Having a Statewide Information and Referral System?" (Melinda Grubbs). A list of exhibitors is provided. (DB)

NATIONAL SYMPOSIUM ON INFORMATION TECHNOLOGY

1992 PROCEEDINGS

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NATIONAL SYMPOSIUM ON INFORMATION TECHNOLOGY

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Edited by:

Donna L. Lesser
Center for Developmental Disabilities
School of Medicine
University of South Carolina
Columbia, South Carolina

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For more information contact:

Center for Developmental Disabilities
Benson Building, 1st Floor
Columbia, SC 29208

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KEYNOTE ADDRESS:

IMPROVING THE USE OF INFORMATION TECHNOLOGY BY INDIVIDUALS WITH DISABILITIES AND THEIR FAMILIES

William H. Graves, Ed.D.
Director
National Institute on Disability and Rehabilitation Research
U.S. Department of Education
Washington, DC

IMPROVING THE USE OF INFORMATION TECHNOLOGY BY INDIVIDUALS WITH DISABILITIES AND THEIR FAMILIES

William H. Graves, Director
National Institute on Disability and Rehabilitation Research

Americans with disabilities are the focus of public attention. Across the nation, people with disabilities and the general public expect that people with disabilities will participate more fully in the work place and in the community. The United States Congress passed and President Bush signed into law on July 26, 1990, the Americans With Disabilities Act, and the ADA. This Act is a legislative symbol of these expectations of the American public, individuals with disabilities will experience greater independence, integration, greater empowerment, more employment opportunities, and richer, fuller lives than individuals with disabilities of past generations.

Disability and rehabilitation research has the capacity to fulfill these expectations of people with disabilities and their families. What is it about disability and rehabilitation research that has the capacity to meet these expectations? What is inherent in research that can meet these expectations of families and people with disabilities? It is both the process of research and the "stuff" produced by research. This "stuff" is knowledge.

The production of knowledge is the chief aim of disability and rehabilitation research. It is knowledge and its use that has the capacity to empower, to support independence, and to increase the freedoms experienced by people with disabilities.

Let me share with you a quotation from the great patriot and scholar James Madison on knowledge and empowerment:

> "A popular government without popular information, or the means of acquiring it, is but a prologue to a farce or a tragedy; or perhaps both. Knowledge will forever govern ignorance: And a people who mean to be their own governors, must arm themselves with the power that knowledge gives."

Knowledge grants people with disabilities and their families the ability to make informed choices. The NIDRR is committed to empowering people with disabilities, their families, and those professionals serving them through providing funding opportunities which produce knowledge and other research products. The mission of NIDRR is to provide people with disabilities and their families the kind of knowledge they need to become empowered and to increase the freedoms they experience.

The NIDRR seeks to join those who are committed to empowering people with disabilities and their families through disability and rehabilitation research. To achieve this goal, NIDRR has implemented recently an information dissemination policy. The goal of the policy,

and of NIDRR, is to encourage the spread of results of research and the utilization of the knowledge produced.

I would now like to talk about the process of research and how the very process of research might stimulate the dissemination of information and the use of "the stuff" produced through the research process.

> Someone once asked Jean Cocteau what he would take if his house were on fire and he could remove only one thing. "Of course, I would take the fire," replied Cocteau.

A smart answer my grandmother might say. By "smart", she would haven't meant bright or intelligent, but rather she would have meant disrespectful. My grandmother, Miss Lily, has little patience with impractical answers nor with answers to questions that were not grounded in her experience of the world around her. Miss Lily knew that no one could take out a fire out of a burning house in the same manner as one would remove a favorite book or album of family photographs from the burning house. Taking the fire out was not practical.

Many people with disabilities, rehabilitation administrators, rehabilitation counselors, and perhaps, even rehabilitation researchers often contend that disability and rehabilitation research is not practical. The research doesn't address problems that are practical. The research is too academic. It is almost or even is esoteric. People with disabilities ask, "Why does the National Institute on Disability and Rehabilitation Research (NIDRR) fund surveys to answer obvious questions?" Or people with disabilities make statements like, "The research that is being done is not helping me solve the problems I have."

Disability and rehabilitation research has a credibility problem. It is viewed not only by practicing rehabilitation professionals as impractical, but often by people with disabilities as irrelevant. The credibility problem points out that disability and rehabilitation research not only has the traditional and age old problem of closing the gap between the research and the end user of the research. It also has the problem that too few view it as worth taking the time to close the gap between research and practice.

Over the years, various strategies have been used by NIDRR to close the gap between research and practice. The assumption undergirding these strategies is that the research conducted by NIDRR grantees has been relevant, addresses questions of concerns to individuals with disabilities, and can be used by rehabilitation professionals such as psychiatrists. The strategies employed by NIDRR have been guided by the legislative mandate of the agency as well as policies developed by its directors as they interpret legislative intent or respond to issues regarding research findings implementation.

The NIDRR legislative mandate provides for research dealing with all age groups and all disabilities. This makes the body of knowledge with which NIDRR deals wide ranging and

complex. Because of the ages covered by Title II of the Rehabilitation Act, NIDRR must address a range of topics that follow a person with a disability from birth throughout his or her lifetime. For example, as Ellen Liberti[1] points out in her paper, "The Dissemination and Utilization of Rehabilitation Research Information by the National Institute on Disability and Rehabilitation Research: Lessons from the Past, Directions for the Future," NIDRR must disseminate medically oriented research findings or specific treatment regimens, protocols for preventing secondary disabilities, statistical materials, information about assistive technologies, information about modifying buildings or worksites, information about products and services, information about the rights of persons with disabilities, and information designed to ease attitudinal barriers and increase the integration of persons with disabilities into all aspects of community life.

NIDRR supports many activities to close the gap between research and practice. These traditional activities are based on the assumption that the research agenda of NIDRR has been and is practical and relevant. The credibility problem that I identified earlier in the presentation is not addressed totally by information dissemination and knowledge utilization activities such as these. Addressing the credibility problem among rehabilitation counselors, psychiatrists, other rehabilitation services providers, and people with disabilities requires a new research model or a paradigm shift.

Participatory Action Research

In traditional approaches to disability and rehabilitation research, the role of the person with a disability is that of a subject, an object to be investigated. The problem investigated is usually defined as a physical, sensory, cognitive, or mental impairment; employability; functional limitations; or lack of motivation and cooperation of the person with the disability. The locus of the research problem is in the individual with the disability. The research strategy is usually determined by the researcher. The strategy is often an intervention designed by the rehabilitation professional or addresses a problem identified by the researcher. The intervention usually focuses on evaluation, training, or home and job site modification. The researcher is in control of the research design from the formulation of the research question to the outcomes promoted to the dissemination of the knowledge produced and the products developed.

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[1] Liberti, E.J. The Dissemination and Utilization of Rehabilitation Research Information by the National Institute on Disability and Rehabilitation Research: Lessons from the Past, Directions for the Future. A paper presented at the American Education Research Association annual convention, Chicago, IL, April 5, 1991.

The research paradigm that will lend greater credibility to disability and rehabilitation research is the approach to research methodology labelled as participatory action research by William Foot Whyte.[2] According to Whyte:

> In participatory action research (PAR), some of the people in the organization or community under study participate actively with the professional researcher throughout the research process from the initial design to the final presentation of results and discussion of their action implications[3].

PAR, in contrast with traditional research, does not treat members of the organization and community as passive subjects. PAR is a research methodology in which members of the community are actively engaged in the quest for information and ideas to guide their future actions and behaviors[4].

As Whyte points out, PAR can be organized in a variety of forms with considerable scientific and methodological demands and possibilities[5]. PAR is an approach that can be applied to research methodologies characterized as quantitative, qualitative, survey research, evaluation studies, and single-subject design. The researcher who uses the PAR model not only works with members of the organization or community in identifying the research question or diagnosing the problem, the researcher also draws upon the research literature as well as his or her own past experience as a researcher or a rehabilitation counselor. PAR helps researchers to be assured that the respondent is answering the question the researcher intended to be answered.

PAR has considerable merit for consideration by researchers, policy makers, rehabilitation professionals, and people with disabilities. Few problems in this field arise in such form that they can be solved by one discipline. No researcher can master all of the disciplines relevant for the problems that rehabilitation counselors encounter. In PAR, the researcher acts less as a disciplinary expert and more as a coach in terms of team building and in seeing to it that as much of the expertise available to the problem solution is capable of being used. PAR enables the researcher and the person with the disability to examine major changes that both helped create[6].

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[2] Whyte, W.F. (Ed.) (1990). Participatory Action Research. Newbury Park, CA: Sage Publications, 2455 Teller Road, 91320

[3] Ibid., p. 20.

[4] Ibid., p. 20.

[5] Ibid., p. 21.

[6] Ibid., p. 40.

The traditional research based on philosophies of science, such as logical positivism, is regarded as setting the standard for scientific rigor. In traditional approaches, the subjects have little or no opportunity to check facts or to offer alternative explanations. Most papers using traditional research approaches read at professional meetings are often subject to criticism from colleagues that the results may be interpreted differently. In this case, researchers often shrug off the comments because their peers who raise the questions didn't have all the data they did when they interpreted the findings. PAR forces researchers to go through a rigorous process of checking the facts with those with first hand knowledge before any reports are written or presented[7].

PAR is a continuous mutual learning strategy. In the traditional model, the researcher operates his or her mental motor at full speed in designing the project. Then the motor shifts to idle as data is collected, usually by research assistants. When the data has been collected, the mental motor shifts to high speed to interpret the results. In PAR, the researcher is constantly challenged by events and by ideas, information, and arguments posed by the project participants[8]. PAR leads researchers to unfamiliar pathways. It stimulates researchers to consider new ideas about old and new theoretical problems thus generating provocative new ideas.

PAR has a number of advantages for disability and rehabilitation research in reducing the credibility problem whether the origin is impracticality - Miss Lily - or irrelevance. By involving the individuals who have the most to gain from the research effort, more relevant questions will be asked, more relevant and acceptable intervention strategies will be developed, more accurate location of the foci of the research will occur, better dissemination strategies will be developed, and more interest and commitment in using the product of the research endeavor will occur. Work by Whyte at Xerox with the support and cooperation of David Kearns, then CEO at Xerox, is an example of the utility of this approach to research[9].

NIDRR will be encouraging the adoption of the PAR approach to disability and rehabilitation research. It will be systemic by including statements in the preambles to absolute and invitational priorities that stress the inclusion of the PAR approach to disability and rehabilitation research.

NIDRR will be encouraging the use of PAR to promote better science. PAR is neither a quantitative nor a qualitative approach to disability and rehabilitation research. Rather PAR is a paradigm that maximizes involvement and participation of the consumer of the research in the

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[7] Whyte, 1990, p. 41.

[8] Ibid., p. 42.

[9] Ibid.

research process and outcome - be that consumer a person with a disability, a parent or a spouse of a person with a disability, or a rehabilitation services provider such as a psychiatrist, rehabilitation counselor, or an assistive technology specialist. PAR is a research paradigm that can be applied to both qualitative and quantitative research. It is one that will enhance the quality, rigor, and usefulness of the research endeavor, and it will strengthen the partnership between the disability and rehabilitation research community and research consumers.

Good science is the key to advances in the quality of life, integration, and inclusion of people with disabilities. PAR is not a substitute for excellence in research design and methodology. It is a way to strengthen the research process. It is also a way to engage the researcher and consumer in a problem solving process that releases the creative energies of both in solving problems that impede the integration, independence, and inclusion of people with disabilities. By involving the individuals who have the most to gain from the research effort, more relevant questions will be asked, more relevant strategies will be developed, more accurate location of the foci of the researcher will occur, better dissemination strategies will occur, and more interest and commitment in using the product of the research endeavor will occur.

The research program at NIDRR must increasingly be one that facilitates empowerment or self-reliance of people with disabilities and their families. The research programs of the RTCs and RECs must be undergirded by empowerment principles. This goal is essentially one of determining the impact of the projects NIDRR funds on the quality of life of people with disabilities.

The rules of the game are changing for professionals who are delivering services as well as for the researcher. Individuals with disabilities will be important and constant members of the education and rehabilitation team rather than occasional players. This involvement is one that offers many opportunities for growth to the professional and to the consumer. I hope you will take advantage of this opportunity for if you do you will surely move closer to your professional goal of enabling people with disabilities to be all that they can and desire to be.

> A famous lecturer was once asked if he found it disconcerting to see members of the audience looking at their watches during a long lecture. "No," he replied, "not until they start shaking them."

I am stopping before you start shaking your watches.

A DISSEMINATION POLICY
FOR DISABILITY AND REHABILITATION RESEARCH IN THE NINETIES

Improving the quality of information disseminated and the frequency of effective utilization of the knowledge and products of research is vital to NIDRR's research program.

There are primarily three ways in which persons with disabilities are empowered--through civil rights, through economic opportunity and through knowledge. The National Institute on Disability and Rehabilitation Research (NIDRR) is fully committed to the empowerment of persons with disabilities. This commitment extends to the conduct of research and the dissemination, and utilization of knowledge--the way in which we can contribute most directly to that empowerment. Through information dissemination and knowledge utilization programs, NIDRR can provide people with disabilities and their families with the kind of knowledge they need to make informed choices, to achieve full empowerment, and to increase personal freedoms.

The NIDRR dissemination goal is to encourage the spread of the results of research and the utilization of the knowledge produced. NIDRR strives to see that the information and knowledge needs of people with disabilities and their families are being met and that information generated by NIDRR-sponsored research is used for further scientific inquiry and improvements in the lives of persons with disabilities. NIDRR must provide information to support education, independent living, and improvements in rehabilitation research and service delivery. The information provided must be valid, timely, and accessible. This is the responsibility of NIDRR to people with disabilities and their families, to those who provide educational and rehabilitative services, to educational and rehabilitation personnel, and to the American taxpayer.

PARTICIPATORY RESEARCH

Persons with disabilities and their families should participate in designing and conducting research. Also, they should be central figures in the dissemination of knowledge resulting from that research. This may mean that in the future NIDRR must change the way research is conducted to achieve participatory research.

Achieving participatory research depends on the intensity of interaction and the commitment of parents, family members, and the educational and rehabilitation practitioners to the products of research. The particular hierarchy of "consumers" for each research project will depend on the nature of the research. It is important that appropriate audiences be identified at the initiation of a research project and that representatives of these groups be involved from the early planning stages. Technical assistance, training, or interpersonal activities that increase the use of knowledge to change attitudes or behavior are appropriate implementation activities.

Upgrading Information Accessibility

NIDRR is committed to upgrading information efforts, to formulating a consistent plan for an information program, and to engaging more people in determining what information should be made available and how we can make it accessible for a variety of audiences. NIDRR has a congressional mandate to disseminate the knowledge and informational materials produced in its programs. It is imperative that persons conducting research, either funded by the Federal Government or sponsored by private institutions, have the benefit of the knowledge generated by NIDRR-funded research.

Research knowledge is a building block upon which creative inquiry can be based. Improving the quality of information disseminated and the frequency of effective utilization of the knowledge and products of research is vital to NIDRR's research program.

NIDRR produces knowledge for various uses. The disability demographics program helps to provide the information upon which the need for research is expressed. Knowing the "state-of-the-art" and what is being done in other funded projects avoids unwanted duplication. Capturing the body of work NIDRR has funded, as well as other information about research results, enables researchers to build upon previous endeavors. Validated practices can be used to improve service delivery.

Strengthening Grantee Dissemination Efforts

NIDRR grantees and other contacts within the wide community of interest in disability and rehabilitation research must assist in demonstrating the importance and vitality of disability and rehabilitation research. Therefore, NIDRR intends to increase the interest of those who are our grantees in strengthening their dissemination and utilization efforts and in involving potential target audiences in the design and conduct of their research. NIDRR also is calling upon them to release, in a timely manner, research information on which they and experts in the field can provide consensus and validation.

NIDRR will sponsor a research consensus validation program in order to find those issues which we can bring to the attention of NIDRR's varied audiences. This process will release from ongoing research that information which is ready to be presented by leading figures in the field and upon which NIDRR can put its stamp of approval. This activity will increase interest and discussion in rehabilitation research, and it will show the importance placed upon the work of NIDRR and its grantees.

The National Institute on Disability and Rehabilitation Research will undertake a program of information dissemination, public education, and knowledge utilization to help create a full and productive partnership among persons with disabilities, their families and representatives, those conducting research, and those engaged in providing services. Knowledge is the key NIDRR brings to this synergism. NIDRR's knowledge dissemination program will make that key available and accessible.

INFORMATION & REFERRAL FOR PERSONS WITH DISABILITIES

THE STRUGGLE TOWARD A COMPREHENSIVE STATE-WIDE INFORMATION SYSTEM

Presented by:

Robert W. Bass, Ph.D.
Director
New England INDEX
Shriver Center
Waltham, MA

Carol Kirchem Price, M.S.S.W
Project Director
Texas Information & Referral Project
Austin, TX

George A. Starr, B.A.
Co-Director
IOWA COMPASS
University of Iowa
Iowa City, IA

THE STRUGGLE TOWARD A COMPREHENSIVE STATE-WIDE INFORMATION SYSTEM

Robert W. Bass
New England INDEX
Waltham, MA

Carol Kirchem Price
Texas Information and Referral Project
Austin, TX

George A Starr
IOWA COMPASS
Iowa City, IA

Development of Information and Referral Systems involves a number of different stages including:

- o needs assessment, seed funding and collaboration,
- o implementation
- o continuation beyond seed funding; and, hopefully,
- o long-term growth

In designing a system, it is difficult, if not impossible, to predict all of the barriers that one might face at each of these stages and plan strategies to keep the project alive.

This symposium takes a look at all of these phases by examining a snap shot of three different state systems at different phases of the life cycle:

- o Texas--moving beyond needs assessment and planning into implementation
- o Iowa--moving beyond implementation and seed funding to continuation
- o Massachusetts--moving beyond continuation into long-term growth

Each participant describes how his or her state has developed priorities, secured funding, and encouraged collaborative efforts to overcome potential barriers. While it is clear that these very different states have approached the goal of a state-wide comprehensive system with a variety of strategies, it is also true that their experiences are similar in many ways. The goal of this symposium is to share some of these strategies, to compare and contrast them, and to develop some common body of principles which apply throughout the developmental cycle.

The Texas Information and Referral Project

This paper will document the evolution of the Texas Information and Referral Project, the goal of which is to develop a statewide comprehensive health and human services information and referral (I&R) system.

Background

Texas has approximately 17 million residents who live in 254 counties spread across 266,000 square miles. Texas is as large as all of New England, New York, Pennsylvania, Ohio, and Illinois combined. In an area this large, there is a great deal of variety in living conditions -- several major metropolitan areas blend with many mid-size communities, and many, many square miles of rural areas. There also is a great diversity of services available -- state health and human services programs are provided through 17 different state agencies as well as thousands of local contractors. However, typically the services available in metropolitan areas as opposed to rural communities are quite inconsistent.

The need for information and referral in Texas has been documented in numerous public forums by consumers as well as agency personnel. There are many stories told about making seven different calls, including calls to other states, only to find the needed services right down the street. Texans are not unique in their need for accurate, up-to-date information. The problem is that information and referral is provided by a variety of independent and autonomous agencies throughout the State who do their business in many different ways. While the major metropolitan areas and some of the mid-size cities in Texas have comprehensive information and referral service providers, the best source of information in the rural communities is often the county judge's office. The implications this hodgepodge of service provision has for the development of a statewide I&R network, particularly in terms of service standardization, communications, data sharing, and technological link-ups between providers are significant.

Project Beginnings

When the Texas Planning Council for Developmental Disabilities (DD Council) conducted a series of public forums around the State to gather consumer input to be used to identify priority needs for the 1990 Report, I&R once again was highlighted as a one of the top three needs in nearly every community.

As a result, the seed for the Texas Information and Referral (I&R) Project was planted. While coordinated I&R for the State of Texas had been a goal in the past from time to time, these efforts usually resulted in the accomplishment of baby steps, but no long-term support for actual systems development.

The DD Council made I&R a priority and searched for a grantee that would develop a plan for building an inclusive system rather than a specialized system targeted solely at a certain group of individuals. The Texas Health and Human Services Coordinating Council was selected because it had a broad scope of responsibility, encompassing the full array of health and human services. In addition, the Coordinating Council had a mandate to develop a statewide I&R system which never had been addressed due to limited resources. The Texas Interagency Council for Early Childhood Intervention (ECI) also participated in the Project because of their federal mandate to develop a central directory of services available for their constituency. ECI saw this cooperative venture as an excellent way to meet their mandate without duplicating efforts. The DD Council provided grant funds to the Coordinating Council to develop a Plan for creating a statewide comprehensive health and human services information and referral system in January 1989.

Assessing

While all three original planning agencies had an interest in I&R services and a commitment to better serving their respective consumer groups, none had experience in providing I&R services. So, the Texas Information and Referral Task Force, a 21-member group of information and referral providers, consumers, state agency personnel, and advocacy groups, was convened and charged to develop the Plan. They began their work with the help of a

consultant who conducted a "State of the State" assessment of I&R in Texas and throughout the country by asking I&R providers what would help them to improve their quality of service and asking consumers what they needed to make I&R services more useful for them. The results of this study were published in the document *Information and Referral in Texas: Needs, Resources, and Opportunities*.

The three most commonly identified consumer needs were for greater **public awareness** of available information and referral services; **improved access** to accurate, current, comprehensive, statewide and local information about available services and general eligibility criteria; and **better coordination** among local, regional, and state information and referral providers.

The two most commonly documented provider needs were for technical assistance in **updating information** on state agency services, and **networking** with other I&R providers to collaborate on ways to better meet the needs of the people they serve.

The study also showed that Texas is virtually teaming with I&R providers who are sincerely committed to helping people find out what they need to know. However, these services are generally fragmented and consist mostly of independent locally-operated services which accomplish their mission in very different ways. In addition, only 12% were automated at that time, although many indicated they were considering automation in the near future.

Planning

With this in mind, the Plan adopted by the Texas Information and Referral Task Force, *Information and Referral in Texas: A Plan to Improve Services*, emphasized building on and enhancing current, existing I&R services in order to create a self-perpetuating statewide network.

The first Task Force Recommendation was to establish a ***partnership*** of business, government, and voluntary organizations to oversee the implementation of the Plan.

The second Task Force Recommendation was to identify all Texas I&R programs meeting the Task Force definition and to publish and distribute a ***directory*** of these programs, to include a profile of information on each program. The Task Force defined an I&R program as one which is formally organized with the primary stated purpose of providing information and referral services. They further noted that the program may be carried out by a discrete organization or as a separately organized part of an organization with a broader mission.

The first edition of the Directory was completed while the Project was still in its planning stages and development of the second edition is currently underway. The book, *Finding Help: A Directory of Health and Human Services Information and Referral Programs*, contains profile information, such as location, hours of operation, counties and target populations served, resource file size, accessibility, computerization, directory publication, etc. on 375 I&R providers in Texas. It is available on diskette in a stand-alone application and in print. The printed version also contains an extensive list of state and national health and human services Helplines.

Finding Help was developed to be a useful tool not only in linking up providers to help them serve their clients better, but also to give them an opportunity to share information when making management decisions, such which software and hardware to purchase or which taxonomy to use.

The third Task Force Recommendation was to establish local and statewide ***networks*** of I&R programs by facilitating awareness, communication, and cooperation among them. This network-building has included developing articles for newsletters; meeting with local I&R providers throughout the State; developing, identifying, and publicizing model I&R programs and services; and making presentations at statewide and national conferences.

The fourth Recommendation was to promote model ***standards*** for I&R programs and provide incentives for and assistance in implementing these standards. This recommendation was in response to a state agency need regarding the possibility of contracting out their I&R programs. They need a set of standards to use to evaluate I&R programs and to ensure that the I&R services they get are of a consistently high quality. Not only is the adoption of these

standards expected to improve the quality and consistency of services, but these standards can also lay the foundation for future steps in building the network of providers. The national I&R standards are currently being used as the basis for the development of these Texas-specific standards.

The fifth and final Task Force Recommendation was to develop an automated ***clearinghouse*** of information on state-provided health and human services including general eligibility requirements, available services, and procedures for applying for services. The implementation of this recommendation should make the maze of state government services much less puzzling and difficult to navigate.

Implementing

With the planning phase completed, the Project moved on to implementation. As we were preparing for this transition, the Legislature made a decision to abolish the Coordinating Council, the agency which had spearheaded the Project to that point. In looking for an appropriate setting in which to begin implementing the Project, it was important that the entity not be an agency which provided a single type of service, so as not to dilute the emphasis on building a truly comprehensive system. As a result, the Project was transferred to the Ombudsman Division of the Governor's Office. This Office provides a statewide generic I&R service for all Texans and conducts investigations where patterns of problems emerge.

When the Legislature met, they were busy indeed. Not only did they exterminate the Texas Health and Human Services Coordinating Council, they also created another umbrella human service agency and incorporated many different pieces related to improving client access to services into the enabling legislation. This major restructuring legislation targets 11 of the state health and human services agencies and mandates that a statewide I&R system be created, that service providers be collocated, that the agencies develop coterminous regional boundaries, and that automation be developed for a consolidated client data base, a centralized scheduling system, a common intake system, and the I&R system. Also included in that legislation was a mandate to develop a common dictionary of health and human

services terms. Finally, these ideas were to be tested out in pilot project sites located in one rural, one metropolitan, and one medium-sized county.

Although the I&R Project did not directly influence the passage of this legislation, the mandated implementation of these concepts could not have come at a better time. With the planning behind us, we have been able to offer some significant insight into how best to implement some of these mandates. Project staff is chairing the committee that is developing common terminology and that group has chosen to use the Infoline *Taxonomy of Human Services* as a base. Additionally, in looking at developing an automated statewide I&R system, we have emphasized the importance of building on the structure and the software that is already available rather than duplicating these efforts.

We are purposely moving slowly in developing our statewide system. We believe that an effective system in Texas can only survive with the support of local providers throughout the State. So, an important piece of our work involves building relationships with those individuals. Technology will be a major consideration as we move forward, but we are not allowing technology to drive the development of the system. Our emphasis currently is on developing the next edition of *Finding Help*, on creating a model I&R program within the Governor's Office, on identifying comprehensive I&R providers in each county, on developing the common dictionary, and on building the partnership that will oversee future Project developments.

Iowa Information and Referral Project

George A Starr, Co-director

IOWA COMPASS

Iowa's quest for a comprehensive statewide information and referral service for people with disabilities began in 1985. That year the fourth edition of the *Iowa Directory of Services for Individuals with Developmental Disabilities* was compiled for the first time using a data base program designed to track questionnaire mailings and survey responses, and to print the camera-ready copy for the *Directory*. The success of this undertaking led to funding from the Iowa Governor's Planning Council for Developmental Disabilities (DD Council) to create the *Electronic Iowa Directory* in 1986. This key word searchable database was available on the American Association of University Affiliated Programs' SCAN network and was basically a data base version of the printed *Iowa Directory*. This data base allowed searches via such criteria as age range, program type, service type, disability, and geographical area served.

In 1987, the DD Council convened an ad-hoc committee to investigate the interest in and feasibility of developing a comprehensive statewide information and referral service for Iowa. The committee consisted of I&R professionals, state and local agency representatives, parents and consumers. A resounding YES was heard from all committee members when they were asked about continuing work on the development of an Iowa I&R project.

The ad-hoc committee's recommendation resulted in the DD Council establishing a Task Force on Information and Referral to prepare an RFP for the design of an Iowa I&R project. This RFP was awarded in 1988 to make recommendations on and reach consensus for the design of a statewide I&R service, and the development of an RFP to implement such a service. Even at

this early stage, inter-agency cooperation was pursued through the involvement of the Iowa Department of Education (as the lead agency for PL 99-457 for the Central Directory component), The Iowa University Affiliated Program and the DD Council, among others. Although there had been on-going discussion about a "computerized" I&R service, no computer requirements were developed for the implementation.

In the summer of 1989, The DD Council awarded the Information and Referral Project to the Iowa University Affiliated Program (IUAP). The IUAP proposed to develop a 5 county (out of a possible 99 counties) pilot information and referral project. This pilot provided research possibilities and testing of data gathering and marketing concepts as well as information service provision. Support was also provided by the Iowa Department of Education, as part of its mandate to develop a Central Directory.

The Iowa University Affiliated Program made a strong commitment to a "consumer operated" I&R service. The need to "computerize" this service was also evident. Marketing and public awareness were likewise identified as critical components. Survey design, provider identification, and taxonomy modifications were all initiated. Off-the-shelf I&R software was purchased, as funds for the in-house development of software were not available. The project got its name, IOWA **COMPASS**, in the fall of 1989. April 1, 1990, was chosen as the day on which IOWA **COMPASS** would begin offering information and referral. An advisory committee was developed, and a project coordinator was hired. It was decided that IOWA **COMPASS** would operate from 7:00 AM to 11:00 PM Monday through Friday, and from 8:00 AM to 12:00 PM on Saturdays; at other times, an answering service would respond to calls. IOWA **COMPASS** would

be staffed by the Project Coordinator and two half time information specialists who were hired in February, 1990.

April 1, 1990 arrived and, as promised, IOWA **COMPASS** "opened its doors." It was two days before we got our first call. The operation consisted of three IBM SX computers (one modified to provide voice output for an information specialist who is blind), dot matrix printers and a TDD/TTY. Even though we were only targeting five counties out of 99, we were able to compile a data base of over 1000 agencies and organizations. Telecom USA* Publishing Division provided free half page ads in their telephone books.

We began working toward full statewide implementation the fall of 1990 The 5 county pilot project had responded to 925 requests for information. Our funding sources still consisted of the DD Council, the Department of Education and the Iowa University Affiliated Program. We acquired phone books for every community in Iowa to identify potential service providers throughout the state that we didn't already now about. We had modified our taxonomies so we needed to re-survey providers already in our data base as well as survey newly identified potential providers. Our provider data base consisted of not only traditional providers but also generic providers -- churches, service clubs and organizations, pharmacies, chambers of commerce, and so forth. We identified over 13,000 potential providers between October and December of 1990. We also worked with Iowa's assistive technology information service, INFO TECH, to cooperate on data gathering in hopes of generating a higher response rate by using a single shared survey.

In January of 1991 we were contacted by the Iowa Department of Public Health to consider taking over TEEN LINE; an information service they had been operating for about four years. TEEN LINE -- Health-Related Information

and Referral for Iowa Teens -- became part of the IOWA **COMPASS** operation with the addition of one half time information specialist. We kept TEEN LINE's original 800 phone number as it was already known throughout the state. The hours of operation for IOWA **COMPASS** and TEEN LINE were now 8:00 am to 8:00 PM Monday through Friday. Two answering services were used for off hours, weekends and holidays.

Our funding levels for statewide implementation were impressive. A huge commitment and a great deal of confidence and hope were evident. All of our funding at this point was federal dollars. Each of our funders, with the exception of the DD Council, had a federal mandate to provide information and referral. We had not yet been successful in obtaining a commitment from state agencies to participate financially. One state appropriation was passed two years in a row only to be line item vetoed because federal dollars were supporting IOWA **COMPASS.** We recognized the need for increased activity to develop long-term, secure state funding as a significant decrease in support from our DD Council was looming only a year away. Looking back on this time, I realize now that the intense level of activity required to build an efficient statewide operation took precedence over acquiring a secure funding appropriation. As with any new service of this kind, it was a classic chicken-or-the-egg conflict. Which comes first, building a successful service that will prove its value and therefore be funded; or securing the funding to build the long-term service? I believe that even as recently as five years ago, acquiring funding from multiple state agencies to operate IOWA **COMPASS** would have required little more than simply asking for an appropriation of $30,000 to $45,000 from each of five agencies. The best laid plans, however, can rapidly fall apart when a state's failing economy makes headlines every day, day after day, month after month. A

$30,000 appropriation today is subject to the kind of scrutiny that a $500,000 appropriation would have received five years ago. Timing, it seems, is everything!

In May of 1991, IOWA **COMPASS** began statewide operations. Increasing one half time position to full time, and adding a full-time information specialist plus a secretary, we boasted a staff of six. The IOWA **COMPASS** computer system was upgraded to a network consisting of a file server and five workstations. Our off-the-shelf software was put back on the shelf as we had almost completed our own, Iowa specific, data base program. In the fall of 1991, The Iowa Mobile and Regional Child Health Specialty Clinics began funding IOWA **COMPASS** to provide information and referral for children with special health care needs, a Maternal and Child Health mandate. IOWA **COMPASS** had a successful operational year. By October, 1991, we had doubled the number of calls from the first year. As of the end of February, 1992, IOWA **COMPASS** had responded to 2,556 requests for information.

Fiscal year 1993 (October of 1992) will, however, see a much different IOWA **COMPASS**. Loss of approximately $150,000 in funding will reduce our staff to only two. Again, a state agency appropriation is possible -- if the allocation recommendation is signed. We have been awarded organizational development dollars, which cannot be used for operations, by the DD Council. IOWA **COMPASS** faces an intense process of re-organizing during FY 93. I am confident that this process, already beginning, will result in "a some parts new and some parts old" IOWA **COMPASS** which will be a stronger, more stable, goal oriented and mission directed organization.

COMPUTERIZED INFORMATION AND REFERRAL IN MASSACHUSETTS

A Journey from Seed Stage to a Long-Term Model

Robert W. Bass, Director
New England INDEX
Shriver Center UAP
Waltham, MA

The purpose of this paper is to trace the development of a computerized state-wide information system for people with disabilities in Massachusetts. The paper will be concluded with a discussion of a long-term vision for comprehensive multi-agency collaboration in maintaining the system.

GETTING STARTED

In 1986, New England INDEX was an organization located at the Shriver Center UAP with a small grant from the federal Administration on Developmental Disabilities to develop a database of services for people with developmental disabilities across New England. This very ambitious project represented a collaboration with other UAPs in New England as well as with several state Developmental Disabilities Councils.

The New England database gave rise to a more comprehensive state-wide project in Massachusetts. Initially, seed monies came from the Massachusetts Developmental Disabilities Council (MDDC) in 1987 to develop software and collect data for the system. The Council's two-year grant was then augmented by support from several branches of the Human Services in Massachusetts (the Department of Mental Retardation, Public Health, and Education) to update and maintain the data.

The underlying objective shared by all of these players was to establish a resource database available to those who provide information and referral to serve people with disabilities, their family and friends, and

professionals who work with them. A strong feature of the system in Massachusetts was the plan to have the information disseminated by those who already were providing I&R, and to have INDEX concentrate on the maintenance and updating of the software and information in it. Initially, dissemination of information was done by a single agency, the Information Center for Individuals with Disabilities, a non-profit I&R agency then funded primarily through the Massachusetts Rehabilitation Commission.

This, then, represented the "seed" stage of this project: funding by five state agencies, recognizing the separate and important functions of software development, data acquisition, and information dissemination.

BEYOND THE SEED STAGE

In some sense, the initial beginnings of a project such as ours represents at the same ttime the most technically challenging, but the also the easiest phase of the project to fund. A strong need was recognized and because there was nothing available to address the need, collaborative support of a number of funders was readily generated. During the development stage, interest was high and we were busy demonstrating the system to people who were very excited about seeing something new and having the opportunity to participate in its development (Much of the initial time spent on the project involved getting input from potential users of the database and users of the information, and thus ownership of the project was widely shared).

Following the initial two years and after we had proudly reported our 96% return rate with our data collection system, we entered a more difficult phase. How do you keep people interested when the excitement has worn off? The updating of the information is extremely time-consuming, tedious, and

costly--not to mention important--but how do you make it interesting enough to keep the funders involved?

It was a problem. The MDDC's initial grant was completed on schedule in 1989, and while we also received a large grant that year to study the feasibility and desirability of a regional information system (from the Administration on Developmental Disabilities), these monies would not support the state-wide effort. An additional problem was that the computer equipment that the UAP invested in the project in 1987 became out of date and we also needed more of it. And if matters weren't bad enough at that point, the much publicized bust of the Massachusetts economy took place, with a resulting cut back in funding from two agencies.

Fortunately, INDEX has been able to deal with these problems through a variety of strategies and developments. First, some private foundation money was sought and received from the John W. Alden Trust. Second, new projects came our way with funding: a DD Council grant to compile data on services for the 1990 report to Congress; a database of Assistive Technology as a result of the U.S. Department of Education (NIDRR)'s grant to the Massachusetts Commission for the Deaf and Hard of Hearing to establish the Massachusetts Assistive Technology Partnership; and, funding from the Agent Orange Class Assistance Program to develop a database of recreation programs. Third, a number of other states as well as some other projects in Massachusetts contracted with INDEX to develop software for them. Monies received for these contracts have been used to pay for equipment as well as support the Massachusetts project itself.

The other major developments that have occurred in addition to fluctuations in funding have been the demands placed upon us to do some new things without additional funding. This obviously required great

flexibility of our staff and some extra work. Since the completion of the development of the initial database in 1989, other databases in the following areas have also been developed, maintained, and disseminated by INDEX: a physicians registry (part of a large Physicians Access Project taken on by our staff in collaboration with another UAP and the state medical society); a Multilingual/Multicultural Resource Directory; a Consultant Registry; and a Parent-to-Parent Network (in collaboration with the Federation for Children with Special Needs). The addition of these projects coupled with the changes to our funding base have provided challenges to our staff, but all our data is still updated annually and each of our projects is active and has taken on a life of its own.

OK, NOW WHAT?

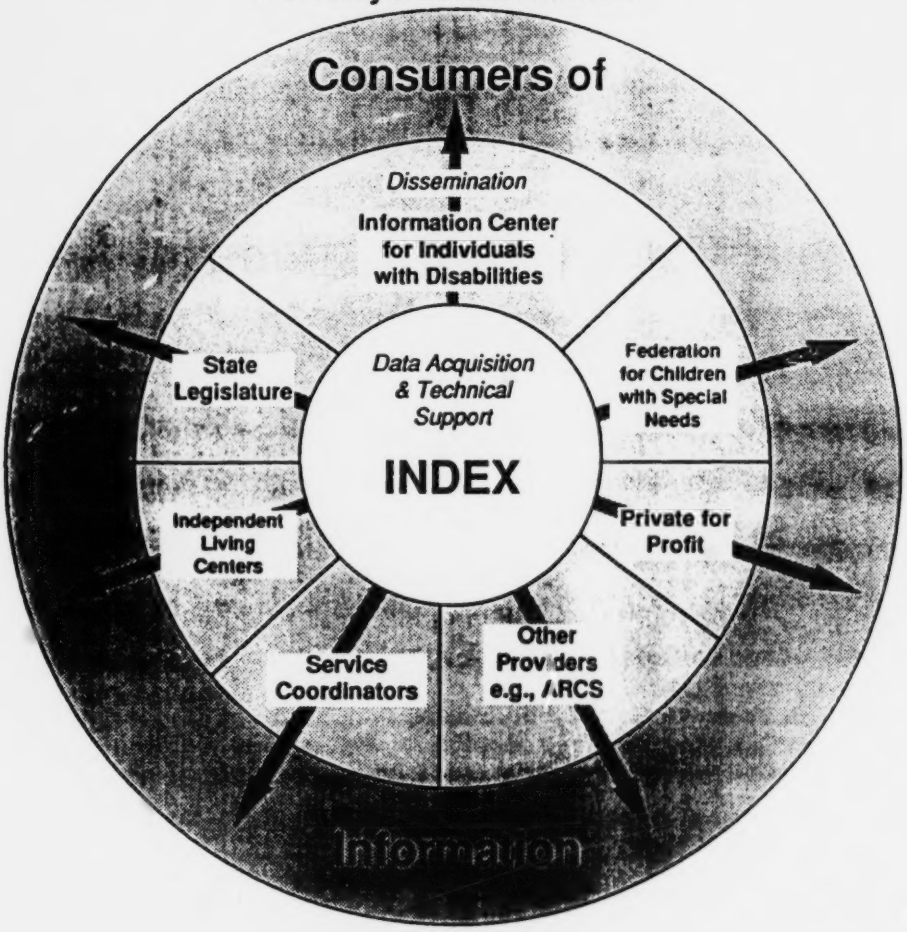
A systematic analysis of the components and functions of the computerized information and referral system in Massachusetts reveals a product that is quite different from that envisioned by all who took part in the initial development in 1987. There are several databases now, and with the advent of the project on assistive technology, dissemination now occurs at multiple sites. Other agencies would like to become additional sites. Each project (and funding source) has its own priorities and sometimes shows little patience with incompatibilities with priorities of others. Is the system still viable? How can the funding continue long-term and the multi-purpose nature of the system continue?

Our response has been to share this interim status with those involved in information and referral in the Commonwealth, to try to include a wider circle of participants, and to look at the opportunities which have now been generated to establish a truly comprehensive system using existing agencies.

In keeping with the entrepreneurial spirit in Massachusetts now, we believe there is also an opportunity for public/private partnership. As a result of consultation with all funding agencies, the Executive Office of Health and Human Services, members of the state legislature, and representatives of the

Proposed

Comprehensive Statewide Information System
Pathways of Information



private sector, a long-term vision has been generated, as shown above. In this model, New England INDEX is seen as the central source of

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information, the coordinator and distributor of the computerized information system (we are also developing alternative methods of dissemination that will allow quicker access to information by consumers). The next layer will be a variety of information and referral agencies, including the state human service departments, private non-profits, and the for-profit sector. These agencies will receive support and training from INDEX as well as constant updating of the information. The final layer is the consumer of information, including both private individuals as well as professionals.

Funding for the system is, of course, the most difficult obstacle and the picture evolves daily. We currently anticipate a subscription cost for each of the state agencies, coordinated through the Executive Office of Human Services. The private sector funding is expected to be limited at first, but hopefully will grow in the percentage as time goes on.

The underlying concepts in the development of the initial system and the model proposed here is that the system should be developed with input and be responsive to the needs of those who will use it; that funding for such a project must be recognized as a long-term need and shared among all those who have a responsibility to this population; and that such as system is both economically and systemically advantageous because it represents a shared resource that is both less costly and more efficient than that that could be maintained by any single source.

TELECOMMUNICATIONS EQUIPMENT AND SERVICES FOR PEOPLE WITH DISABILITIES

Presented by:

David Baquis, B.A.
Assistant Director
Tele-Consumer Hotline
Washington, DC

TELEPHONE COMMUNICATIONS FOR PEOPLE WITH DISABILITIES

By David Baquis
Assistant Director, Tele-Consumer Hotline

INTRODUCTION

People with disabilities present a wide range of challenges regarding their need for special telephone equipment and services. The good news is that an increasing number of technological solutions are available to enhance their access to the telephone network enabling them to lead self supporting lives.

However, with this technological explosion, the need for clear information about cost and availability of assistive devices continues to rise. Technology information is requested by end users as well as the professionals who serve them: rehabilitation counselors, telephone company executives, social workers, therapists, advocates, legislators and others.

TELE-CONSUMER HOTLINE

The Tele-Consumer Hotline is a service that helps fill this information gap. Founded in 1984 by the Consumer Federation of America and the Telecommunications Research Action Center, the Hotline originally answered questions about long distance selection.

The Hotline, a 501(c)3 non profit organization, incorporated as an impartial and independent service and broadened its scope of services to include counseling on more than 20 other telephone issues such as: consumer protection; budgeting phone dollars;

repairs; phone selection; starting service; operator services; enhanced local services; telephone fraud; reducing annoying calls; pay-per-call services and low income assistance programs.

The phone industry experienced perhaps more dramatic changes over the past decade than any other industry in the history of America. Many of these market changes affected people with disabilities. For example, after the divestiture of AT&T, consumers in some areas were no longer able to obtain much needed special equipment through their local phone companies.

In 1986, the Hotline developed a Special Needs Program to meet the unique informational needs of persons with disabilities and of those who associate with them. One-fourth of all Hotline inquiries relate to disability issues. The Hotline offers a number of publications on disability issues such as: a Shopper's Guide to Special Telephone Equipment; a list of Text Telephone directories; a comparison chart of relay services and a factsheet describing special services phone companies offer for people with disabilities.

Since the Hotline built a strong track record of educating the public on <u>all</u> telephone concerns before expanding into disability issues, Hotline counselors could answer technical questions that organizations which specialized <u>only</u> in telephone issues or <u>only</u> in disability issues may not have understood.

The Hotline possesses the unique structure of a highly effective corporate/consumer partnership. Phone companies (local as well as long distance) fund it, yet leaders of major consumer groups such as the American Association of Retired Persons (AARP) actually control the Board of Directors. This keeps the Hotline privy to detailed and accurate information, shared in a timely manner by the industry. Yet all Hotline publications are channeled through an Advisory Committee, which ensures that the information is in the consumer interest.

PUBLIC POLICY AND DISABILITY INFORMATION

Although the Hotline specializes in telephone-related issues, there are several other programs that provide information on special technology in general including some information on telecommunications. A list of all groups that significantly contributed to education on telephone disability issues would be too long to share in its entirety. Those in the forefront include the 31 states which received grants from NIDRR (the Department of Education National Institute on Disability and Rehabilitation Research) under the "Tech Act", formally known as the Technology-Related Assistance for Individuals with Disabilities Act of 1988.

The purposes of the Tech Act include increasing the awareness of consumer needs, public policies, and funding mechanisms that relate to assistive technology (AT)/1. Additional studies, training and demonstration projects are funded on such issues as national information and referral network feasibility and financing AT devices and services.

NIDRR also funds 10 centers to provide information on the Americans With Disabilities Act of 1990 (ADA). These Regional Business Accommodation Centers (RBACs) will disseminate information and provide training on the ADA to businesses, employers, civic groups and persons with disabilities.

A number of other federal mandates, such as the Hearing Aid Compatibility Act of 1989, continue to help people with disabilities by recognizing opportunities available through improved technology. The Telecommunications Accessibility Enhancement Act of 1989 directs the Federal government to ensure that the federal telecommunications system is accessible to persons with hearing and speech impairments. Section 508 of the Rehabilitation Act amended in 1988 directs the Federal government to ensure that electronic office equipment is accessible.

CONSUMER CONCERNS

Consumer questions range in degree of difficulty from those of novices, such as "What is a TDD?", to challenges from highly experienced consumers. Examples of technical questions include: "Can I use my personal computer to communicate with a text telephone user?", "Can I answer and hang-up hands-free using a voice activated phone?", "How do I attach a headset or speakerbox to a phone for use in conjunction with the voice-carry-over feature of a relay center?"

The most common question presented to the Hotline is "Where can I obtain a specific item of special equipment?" This is

followed by "What type of equipment is available to help with a specific challenge?" and "How much does it cost?"

This order of popularity in AT questions means that most consumers contacting the Hotline about AT already know the type of equipment they want. It also appears that their concerns about accommodation outweigh their feelings about cost.

There are two inferences, however, which should not be made. The first is that consumers don't care about cost. Actually, when conducting research to prepare the Shopper's Guide to Special Telephone Equipment, the Hotline discovered price differences of as much as $100 on identical items from different vendors. Many consumers remarked on the value of this information in satisfaction surveys conducted by the Hotline.

The second fallacy, far more common, presumes consumers always make accurate self assessments. The Hotline frequently speaks with consumers who made poor selections because they did not know all the equipment options. Sometimes, they had multiple challenges and obtained a device that accommodated only one of their needs.

For example, when someone asks about an amplifier, a counselor probes whether he or she misses calls. Often it becomes apparent that the consumer may benefit from a loud bell or light signaler. Nevertheless, in an effort to empower

consumers, Hotline counselors always give weight to caller's assessments of their own needs. The ABLEDATA Information Broker Handbook is a resource which offers a good checklist of questions to ask about consumers and AT desired/2.

ADDCs

The issue of a thorough needs assessment underscores the value of Assistive Devices Demonstration Centers (ADDCs). ADDC showrooms of special equipment allow people to use and discover for themselves the most effective equipment for their needs.

Some centers are staffed by experts who work by appointment and explain the pros and cons of each device. They may use the assistance of the ABLEDATA computer database on AT. Some offer to sell the types of models displayed. Obviously, this hands-on process is much better than trying to guess appropriateness by reading a catalogue. Unfortunately, there are not enough ADDCs outside major cities.

The Hotline is currently compiling a comprehensive chart of ADDCs, which will offer details on the type of products displayed. Most ADDCs are geared towards the needs of the hearing impaired.

PUBLIC EQUIPMENT DISTRIBUTION PROGRAMS

A number of programs exist to help consumers obtain AT. The differences among the programs are vast, and some programs have changed over time, due to the temporary nature of their funding. The Hotline is preparing a matrix detailing the

differences among the programs.

All funding options have advantages and disadvantages that can lead to tense political climates between equipment distributors and others. For example, a program that buys the equipment wholesale may save money. However, programs which issue vouchers allow consumers to select models best suited to their needs and simultaneously patronize the regional equipment vendors.

Some states have more than one program, while other states offer none at this time. This gap may diminish as more states develop equipment distribution programs. The absence of programs in some states has been a matter of priority. Many advocates focused on establishing a relay center first.

Incidentally, states which establish equipment distribution programs in the future may see a corresponding rise in calls from Text Telephone users to the relay centers. The converse is also true: after establishing rapport with Text Telephone users through the relay system, many non-disabled people obtain Text Telephones.

RELAY SERVICES

Much attention has been focused on relay services as they have developed into a $250 million dollar industry/3. In 1987, the Hotline reported on a survey of more than 300 relay services, most of which were operated on a voluntary basis by non profit agencies/4. Although services have regionalized and improved

through automation and standardization, telephone service will continue to seem complex from the consumer perspective.

For example, the issue of equal access to long distance services has not yet been addressed by all relay services. Some consumers cannot select the company through which their relay service handles long distance calls. In the future, relay consumers in some areas may be required to use one relay center for local calls and another relay service to reach their preferred long distance carrier.

Some consumers have expressed a desire to streamline relay services to a single number for access. This suggestion presumes that all relay services would offer the same features. However, many differences, such as capacity to handle calls in different languages or the option to interpret instead of transliterate the conversation, exist even between relay centers which meet the federal mandates.

SAMPLE SOLUTIONS

The following suggestions serve as possible solutions to specific telephone related challenges of some consumers. Often, needs can be accommodated in a number of ways. The selection of an assistive device or service will depend in part on the consumer's preference and ability.

PROBLEM: A text telephone user (deaf) answers the phone but receives no response.

SOLUTION: Use Caller ID (a local phone company service) to

identify the phone number of the caller. Then return the call to the presumed hearing person through a relay center.

PROBLEM: A household with deaf and hearing members receives both voice and text telephone calls on the same line. The deaf person is unable to speak with hearing callers.
SOLUTION: Use distinctive ringing. The phone company will assign two numbers to their line. The deaf person will advise text telephone users to call on the number designated to ring (or flash) with a distinctive pattern when dialed.

PROBLEM: A person cannot afford a text telephone and no public distribution program is available to lend one.
SOLUTION: Consider purchasing a text telephone on an installment plan through a national organization. Also consider purchasing a reconditioned one for less than $100 through a number of TDD dealers.

PROBLEM: A person with a cognitive impairment becomes confused when dialing a sequence of numbers, such as when dialing or when using voice processing services.
SOLUTION: Use visual or auditory feedack. For example, obtain a phone which provides voice synthesis when a button is pressed on the key pad or consider using a phone with a LCD display of the phone number dialed.

PROBLEM: A consumer with low income needs a Personal Emergency Response System (PERS). The same person received sales pitches

about PERSs priced at thousands of dollars.

SOLUTION: Lease a system through a local hospital or community agency. Prices average $30 per month including the fee for the monitoring service.

PROBLEM: A person with limited mobility cannot reach his phone before it stops ringing. The phone is across the room. He was previously advised to install a new jack.

SOLUTION: Buy a phone extension cord for less than $10 and attach it himself to bring the phone closer to his chair.

PROBLEM: Person cannot afford an amplifier and no public distribution program is available to lend one.

SOLUTION: Lease one for less than $1 per month from a national company.

PROBLEM: Consumer recently lost her vision and frequently misdials numbers.

SOLUTION: Obtain a free sticker for her rotary dial phone. The sticker features raised numbers which she can feel with her fingertips.

MARKETING CONSIDERATIONS

The cost of AT is high. This is not merely due to the expense of subsidizing research and development, but because many AT products are created for a small market. Yet, it is important not to underestimate the size of the population of people with disabilities. More than 43 million people are estimated to experience some degree of impairment. In fact, some people

without disabilities consider themselves "temporarily able-bodied" because they recognize that, at some point in the future, they may experience a disability.

It should also be noted that all impairments except speech impairment have their highest rate of occurrence among elderly people. Therefore, with the increase of older people in the United States, it is reasonable to assume more and more people will be affected by impairments that restrict telephone use/5.

On the other hand, it is important not to overestimate the prevalence of people with disabilities and run the risk of forecasting an optimistically high market potential/6. In general, approximately 14% of the United States population reports a limitation relative to one or more major life activities. Yet little demographic information is available at the level needed by businesses and the telephone industry. Nevertheless, the World Institute on Disability compiled estimates of the number of people who are potentially limited regarding use of telecommunications [SEE APPENDIX E].

SECONDARY BENEFITS

Rehabilitation equipment is generally marketed to prescribers, users and payers. It is interesting to note, though, that some accommodations intended initially to help people with disabilities benefit others as well. Some disability activists call these accommodations "electronic curb cuts". For example, amplification from pay phones may help people calling from noisy areas as well as people who are hard of hearing.

The reverse is also true. Although some solutions, such as relay services for the hearing impaired, are intentional accommodations. Other solutions, such as cordless phones for people with mobility impairments, are incidental. In other words, some devices were developed for reasons of convenience and were later noted to have a secondary benefit for persons with disabilities. Some companies acquire AT out of consideration for people with disabilities or to conform with public policy. Obviously, however, a company that meets the needs of a group much larger than intended draws a good return on its investment. In other words, the change or addition may produce revenue, increase good will, reduce losses and help in ways not initially expected by the company.

Over the past 5 years, programs have become increasingly consumer responsive. Improvements in the Operator Service for the Deaf serve as a good example. Nevertheless, attention should continue to be focused on the needs of all consumers. Sometimes accommodations for one group become barriers for another. For example, while ANI (automatic number identification) services offer promise for the deaf, they cannot be fully utilized by people who are blind. The benefits and drawbacks are reversed with audiotext yellow pages.

GAPS

As a result of the ADA, telecommunications access is no longer a luxury -- it has become a right. However, several fundamental issues in telecommunications remain to be addressed. As an example, services not available to text telephone users

include: operator emergency interrupt; voice processing services through relay centers, and speech to text. Areas deserving further attention include access to emergency response centers, and text telephone electronic mail.

As changes have propelled society into an electronic information age, the need for accommodation is now critical. A key concept in future telecommunications technologies is transparency. In other words, the telephone network will feature advanced technologies (which will ultimately provide more services), yet should offer a smooth transition from current technologies with which more consumers are familiar and at ease.

CONCLUSION

Information specialists play a key role in assisting consumers. They can begin by making their own materials accessible (within reason). Formats and accommodations to consider include: large print, braille, 4-track cassette, captioning, text telephone accessibility, wheelchair accessibility, computer "on line" accessibility and bilingual staff.

Two additional areas in need of improvement are knowledge of products and services on the market and utilization of a systematic selection process. This includes gathering information about an individual's abilities, the task to be accomplished, and the performance environment. For the most part, this process is an art learned through apprenticeship.

ENDNOTES

1 Information on the Tech Act was generously provided by RESNA (Rehabilitation Society of North America), which is an organization concerned with the application of science and technology to rehabilitation. RESNA was awarded a contract to provide technical assistance to the states, including a quarterly newsletter and a directory of expert consultants.

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5 Telephone Services and Equipment for Disabled People, Rehab Brief -- Bringing Equipment into Focus, NIDRR, 1984.

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APPENDIX A

IMPAIRMENT: HARD OF HEARING

1.) Loud Ringers
(Devices which help you hear the phone ring)

2.) Personal Emergency Response Systems
(Devices which alert a monitoring service to a medical emergency)

3.) Squeal Inhibitors
(Devices which reduce the annoying whistle from hearing aids)

4.) Teaching Aids
(Materials or equipment for instructional use)

5.) Volume Controls
(Devices which increase listening volume)

a.) Amplification Handset
b.) Amplification Telephone
c.) Auxiliary Amplifier
d.) Portable Amplifier

IMPAIRMENT: DEAFNESS

1.) Answering Machines
(Specially modified phone answering machines for the deaf)

a.) Text Telephone Answering Machines
b.) Text Telephone/Voice Answering Machines

2.) Fascimile (FAX) Machines
(Equipment which allows you to send copies of documents over the phone lines)

3.) Personal Emergency Response Systems
(Devices which alert a monitoring service to a medical emergency)

4.) Ring Signalers
(Devices which alert consumers to the sound of the phone ringing)

a.) Light Flashers
b.) Vibrators

5.) Teaching Aids
(Materials or equipment for instructional use)

6.) Video Display Terminals
(Devices which allow people who are deaf or deaf-blind to converse over the phone)

a.) Computers with Modems
b.) Telebrailles (visual/tactile)
c.) Text Telephones
d.) Touch Tone Decoders

IMPAIRMENT: SPEECH

1.) Artificial Larynxes
(Devices which vibrate to help a person create speech)

2.) Auxiliary Speech Amplifiers
(External box systems which increase speaking volume of people with weak speech)

3.) Fascimile (FAX) Machines
(Equipment which allows you to send copies of documents over the phone lines)

4.) Personal Emergency Response Systems
(Devices which alert a monitoring service to a medical emergency)

5.) Tape Players
(Devices which enable speech impaired people to play prerecorded messages)

6.) Teaching Aids
(Materials or equipment for instructional use)

7.) Video Display Terminals
(Devices which allow people with a speech impairment to converse over the phone)

a.) Computers with modems
b.) Text Telephones
c.) Touch Tone Decoders

8.) Voice Synthesis Equipment
(Devices which produce artificial speech)

9.) Volume Control Receivers
(Handsets which amplify speaking volume of people with weak speech)

IMPAIRMENT: VISION

1.) Audible Light Sensors
(Devices which emit a sound to indicate the status of phone lines)

2.) Answering Machines
(Specially modified answering machines which help deaf-blind people receive phone messages)

3.) Auto Dialers
(Devices which can dial a preprogrammed number)

4.) Big Button Phones
(Phones with enlarged buttons on the keypad to help prevent misdialing)

5.) Computers with Special Software
(Software can aid with dialing, retrieving phone numbers, and more!)

6.) Dialing Aids
(Units which attach to phone and help prevent misdialing)

7.) Headsets
(Devices which allow you to speak hands-free and with privacy)

8.) Personal Emergency Response Systems
(Devices which alert a monitoring service to a medical emergency)

9.) Speakerphones
(Devices which allow you to talk hands-free into the phone)

10.) Teaching Aids
(Materials or equipment for instructional use)

11.) Visual Display Terminals
(Devices which help people who are deaf and visually impaired converse over the phone)

a.) Computer/ TDD Modems (with enlarged display or braille output)
b.) Telebrailles (visual/tactile)
c.) Text Telephones (with enlarged display)

IMPAIRMENT: MOTION

1.) Answering Machines
(Devices which allow you to exchange messages with callers when you are unable to answer the phone)

2.) Auto Dialers
(Devices which can dial a preprogrammed number)

3.) Big Button Phones
(Phones with enlarged buttons on the keypad to help prevent misdialing)

4.) Computers with Special Software
(Software can aid with dialing, retrieving phone numbers, and more!)

5.) Cordless Phones
(Phones which provide you with mobility to answering the phone from wherever you are)

6.) Customized Phones
(Varying switches enable severely challenged persons to use their residual abilities to operate a phone)

7.) Dialing Aids
(Devices which attach to phone and help prevent misdialing)

8.) Handset Helpers
(Devices which help you hold the phone receiver)

9.) Headsets
(Devices which allow you to speak hands-free and with privacy)

10.) Personal Emergency Response Systems
(Devices which alert a monitoring service to a medical emergency)

11.) Speakerphones
(Devices which allow you to talk hands-free into the phone)

12.) Teaching Aids
(Materials or equipment for instructional use)

13.) Touch Sensitive Phones
(Phones which can be dialed with a feather-like touch)

PURPOSES OF THE TECH ACT

1. Increase awareness of the needs of individuals with disabilities for assistive technology devices and services

2. Increase awareness of policies, practices, and procedures that facilitate or impede the availability or provision of assistive technology devices and services

3. Increase the availability of and funding for the provision of assistive technology services and devices for individuals with disabilities

4. Increase awareness and knowledge of the efficacy of assistive technology services and devices among individuals with disabilities, their families, professionals, service providers, employers, and other appropriate individuals

5. Increase the capacity of public and private entities to provide technology-related assistance to pay for the provision of assistive technology devices and services

6. Increase coordination among State agencies and public and private entities that provide technology-related assistance

7. Increase the probability that individuals of all ages with disabilities will, to the extent appropriate, be able to secure and maintain possession of assistive technology devices

Taken from the *Technology-Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407)*

APPENDIX C

TELEPHONE DISABILITY ISSUES

EQUIPMENT:
- WHAT IS AVAILABLE
- WHERE TO OBTAIN IT
- HOW MUCH DOES IT COST
- HOW TO INSTALL IT
- WHERE TO REPAIR IT
- WHERE TO LEASE IT OR BUY IT RECONDITIONED
- AVAILABILITY OF EQUIPMENT DISTRIBUTION PROGRAMS

RELAY CENTERS:
- WHAT ARE THEY
- WHAT IS THE NUMBER OF A SPECIFIC SERVICE
- HOW TO USE THEM

PHONE COMPANY:
- TT* TOLL CALL DISCOUNT
- DIRECTORY ASSISTANCE EXEMPTION
- OPERATOR ASSISTANCE EXEMPTION
- LARGE PRINT, BRAILLE OR CASSETTE TAPE FORMATS
- BUSINESS OFFICE TT NUMBERS
- SPECIAL NEEDS CENTERS
- CLASS (CUSTOM LOCAL AREA SIGNALING SERVICES)

BILLING:
- HAS THE DISCOUNT OR EXEMPTION BEEN APPLIED
- HOW TO RESOLVE BILLING DISPUTES
- LOW INCOME ASSISTANCE/ OTHER MONEY SAVING TIPS

TT DIRECTORIES:
- WHAT ARE THEY
- WHERE TO OBTAIN THEM
- HOW TO GET LISTED

PUBLIC POLICY:
- WHAT ARE THE ADA RULES
- DO THE RULES APPLY TO ME (BUSINESS)
- WHO CAN ADVISE ME

OTHER:
- TT OPERATOR
- NEW DEVELOPMENTS IN ASSISTIVE TECHNOLOGY AND SERVICES

* TT stands for Text Telephone, which is the term suggested by the FCC (Federal Communication Commission to replace TDD (Telecommunication Device for the Deaf). TDDs were originally called TTYs (teletypes).

APPENDIX D

EQUIPMENT DISTRIBUTION/ FINANCING PROGRAMS

PROGRAM TYPE	EQUIPMENT OWNERSHIP
1.) Donating	(consumer)
2.) Cost-sharing	(consumer)
3.) Voucher-system	(consumer)
4.) Low or no interest loan	(consumer)
5.) Lending	(distributor)
6.) Leasing	(distributor)

Programs may impose eligibility requirements based on any of the following features:

A.) Income status (e.g., low income only)

B.) Geographic residency (e.g., state residents only)

C.) Local phone company jurisdiction (e.g., independent or Bell Co)

D.) Telephone subscribership (e.g., must have a phone line)

E.) Class of phone service (e.g., residential or business)

F.) Impairment certification (e.g., only hearing or speech impaired)

G.) Need/ Priority (e.g., only one per houshold)

H.) Age (e.g., must be over 9 years old)

I.) Skill (e.g., ability to use TDD or to read braille)

Prevalence Estimates for Noninstitutionalized Persons in the United States with Conditions Which Might Affect Use of Telecommunications, by Condition and Age [in thousands (000)]

Chronic Conditions	All Ages	0–7	18–69	0–45	45–69	70+
All Causes	32,540	3,192	22,524	11,572	14,144	6,824
Degree of Activity Limitation						
Unable to Perform Major Activity	8,825	256	7,286	2,312	5,230	1,283
Limited in Amount and Kind of Major Activity	13,642	1,995	9,284	5,681	5,598	2,362
Limited in Non-Major Activity	10,073	941	5,954	3,579	3,316	3,179

(c) World Institute on Disability

AIRS & NSIT - WILL THE TAIL WAG THE DOG?

Presented by:

Charles Juhn, M.A.
Information Specialist
Utah Assistive Technology Program
Utah State University
Logan, UT

AIRS and NSIT - Will the Tail Wag the Dog?

AIRS, the Alliance of Information and Referral Systems, Inc. is in a sense a 'sleeping giant'. The advent of the Americans With Disabilities Act, changing funding patterns, subsidized programs for special interest groups from the aging to minority groups to persons with disabilities has made cooperation among I & R providers, and parent organizations, extremely important. National organizations representing various constituencies should articulate closely to maximize information sharing among themselves to foster cooperative development of resources at all levels from community to nation. NSIT, the National Symposium on Information Technology, is a key event where I & R providers representing the 'disabilities' community gather. This powerful group can significantly impact AIRS as an organization, and information and referral as a service.

Introduction

Information technology is revolutionary, and has implications from the individual level to that of the world 'body politic'. Particularly in areas where control of information has been under the aegis of various government agencies and therefor vulnerable to manipulation traditional to a hierarchical structure, current technology related to acquisition and dissemination of information gives people at all levels the ability to access tremendous amounts of information without it being filtered or withheld. This fact has major implications for each of us because information processing is a component of all social activities, and current technology has gone far towards levelling the playing field for the participants, regardless of economic, social, or physical condition. The technology that gives access to information is still, however, part and parcel of the various social structures that fund, design, compile, and build various information systems. It is this fact that makes communication among those agencies and groups who develop and invest in such schemes extremely important because the opportunity exists to share resources. This sharing of resources at all levels translates into one specific and extremely important point, which is that users of information can get the best, most comprehensive, highest quality information they need easily.

Current technology allows us to process information at speeds previously unknown, and share that information in ways that often circumvent or bypass the traditional information dissemination

mechanisms. In fact, individuals can access information using a personal computer and a telephone anywhere in the world through in-place technology that includes the telephone system, satellites, and computer 'gateways'. Optical media (CD-ROM's) allow huge databases to be mailed to users anywhere, and desk-top computers with storage in the range of gigabytes are soon to be available. A future that includes 'gobots', i.e. information gathering 'traveler' programs tailored to individual needs, the 'information grid', 586 and 686 chips, and advances in biotechnology all imply massive change in the information field will occur, whether it be for good or ill (Miles, 1988; Mayfield-Smith, 1990).

This paper's focus is on how information and referral systems (I & R's) can serve as a 'glue' in developing social, political and economic structures that account for and respond to those who need to access information. It is concerned with how some major organizations may impact accessibility to certain kinds of information by dint of the format information is collected and stored in, how it is accessed, who pays for it, and how 'turf' issues may be of importance.

What is Information and Referral (I & R) ?

According to Risha Levinson, in her comprehensive work Information and Referral Networks: Doorways to Human Services (Levinson, 1988), 'there is no single, universally accepted definition of I & R, nor is there a single model that represents an ideal or typical service' (Levinson, 1988, p.7). Given the above,

Levinson suggests the following two-part definition, which seems to well encapsulate the functions of a true information and referral service:

> 1. The purpose of I & R is to link the inquirer with an available, appropriate, and acceptable service.
>
> 2. Further, to utilize the data of an I & R reporting system for purposes of social planning, program development, outreach, advocacy, and evaluation (Levinson, 1988, p.7).

This paper proposes that in addition to the above the role of formal information and referral organizations must also strive:

> 3. To improve the efficiency of data collection and storage of information by minimizing duplication and maximizing sharing of resources through I & R mechanisms.

In discussing 'I & R' as an activity there also appears to be a definite striation between information and referral activities that may be called 'generic', i.e., systems supplying information on all types of activities and resources to any caller regardless of situation, and 'specialized', i.e., those systems that provide information specific to a particular area and/or need such as 'Ask-A-Nurse', 'Community Support Line', 'Assistive Technology Helpline', 'Crisis Line', or any one of a dozen others.

One of these more specialized information activities provides information directed towards assisting people with disabilities, and it is the premise of this paper that activities ongoing in this area will significantly affect I & R provision at all levels from community to nation in the not far distant future. For a number of reasons, activities related to hardware and software production,

equipment information databases, service delivery databases, and bibliographic databases have expanded rapidly in the last 4 years. Due to recent legislation regarding the Americans with Disabilities Act, the Technology Act (PL 100-407), and continued efforts in areas related to aging, this major subset of information and referral activities is becoming a powerful force in I & R. Money, programs, legislation, and talent have converged in this area to a significant degree, and the impact is being felt. More importantly, structural and programmatic work now just being completed or on the books will have a major influence on the continuing development of the field of I & R as it applies to information services for people with disabilities. This paper proposes that these developments may have major implications for 'generic' information and referral activities. It is important that during these formative stages the major players make every effort to synthesize and consolidate efforts to maximize resources and make information exchange as practicable as possible.

The following sections will give a brief history of I & R in the U.S., outline some of the major groups working in the area of I & R, and suggest that work being done by those groups closely affiliated with services and programs directed towards persons with disabilities could have a major impact on how I & R is accomplished, be it generic or specialized.

History

Organized I & R activity as we know it is essentially a

product of World War II, with the groundwork primarily laid in Britain. Because of the large numbers of displaced persons, returning military people, and the difficulties in knowing and accessing exactly what was needed to meet a plethora of social needs that were the result of the war years, the British developed what was known as the British Citizens Advice Bureaux (CABs). The British system in fact preceded significant I & R developments in the United States by about 20 years (Levinson, 1988).

Although there was some formal I & R activity in the U.S. prior to the second world war, primarily accomplished by non-governmental organizations providing humanitarian services, the years immediately following the war saw greatly increased activity in I & R. Veteran's Information Centers (VIC's) were established to facilitate the reintegration of military people into communities, but this was a relatively short lived phenomenon. In the 1960's, however, I & R as a recognized activity came into its own. The passage of the Older Americans Act in 1965 included a major program focus on information and referral and one very important aspect of the I & R services provided through the OAA was that many of the resource files and personnel were located in community libraries (Levinson, 1988). This was only one of a significant number of programs initiated by local, state, and federal mandates that were directed at improving services through formal information mechanisms to various disadvantaged groups or economic regions, but probably had the greatest overall impact in I & R development in the long term in the U.S.

The decade of the 60's set the stage for a proliferation of generic and specialized I & R activities in the U.S. that has resulted in a huge range of I & R activities across the nation today. This, coupled with a technological revolution that has made the transfer of raw information as efficient as piping gasoline or electricity in the national grid, has opened the information world to an unprecedented extent. As I & R activity proliferated, one area of major importance in the field was the provision of services to persons with disabilities. In attempting to address unique needs of this group complex databases and computer software packages have been developed that have influenced the way much I & R is accomplished, or will be, in the U.S. This will be an important factor in the next decade due to the fact that a great deal of the computer software developed to manage information pertinent to persons with disabilities applies as well to generic I & R service providers. Because this software was developed using federal monies in many cases it is non-proprietary and thus freely distributable. This is potentially an extremely important factor in the way computerized I & R systems will develop in the U.S. even though there is no specific central organizational body mandating particular standards.

Access to services was the traditional focus of I & R, but the technological advances seen in the 70's and 80's, especially in computer technology, demonstrated the need for increased information specifically about technology available for persons with disabilities. Public Law 100-407, passed in 1988, ushered in

the age of technology for persons with disabilities, and one of its mandates was that information about technology useful to persons with disabilities be disseminated as widely as possible. This helped to spur development of user friendly softwares to manage huge databases that have laid the groundwork for very sophisticated, user accessible information systems. One of the major and key developments was that of Greg Van Derheidens 'HyperAbledata' system.

I & R Structures

Because there seems to be some movement towards a more formal I & R structure in the U.S. at this time, it will be useful to briefly compare the U.S. and British models. The essential differences between the British CAB model and the U.S. I & R model could probably be encapsulated in 3 main areas (Levinson, 1988): 1) Organizational; 2) Service Delivery; and 3) Policy. The CAB's are much more formally organized and have a well defined hierarchical relationship to a national body. Some functions are centralized but the local CAB retains significant functional autonomy. The I & R's of the United States do not function within an organizational hierarchy, and each I & R is a completely independent entity. There is a national association of I & R's, the Alliance of Information and Referral Systems, Inc. (AIRS), but they do not govern the activities of the members. In terms of service delivery, both provide mediated services, but the CAB's have more 'walk-in' activity than their U.S. counterparts, whose method of

entry is generally by telephone. CAB's also appear to depend more on volunteer staffing than U.S. I & R's (Levinson, 1988). An important difference, and one that has very real implications for information sharing, is that the CAB's use what is called a 'Uniform Information System' that articulates at all levels from local to national.

In contradistinction, the I & R scene in the U.S. is one of great diversity in terms of service delivery language, taxonomy, and information formats and protocols. There is significant work in the U.S. to develop better methods for insuring that collected information is transferable (Sales, 1987; United Way of America, 1973) and includes research and development at the TRACE Center in Madison, Wisconsin and Division of Information Technology at the Center for Developmental Disabilities, University of South Carolina. This is important because computer technology is making it more and more possible to share massive amounts of information. The need exists to have standards for information collection, storage, update and transfer if this information is to be widely exchanged. At this stage, it appears that there are three major players in the area of taxonomy, format, and organization of collected data and include: 1) TRACE Institutes 'HyperAbledata' system, the 'Service Delivery Directory', and possibly a bibliographic section to manage literature, video materials, etc. 2) Info-Line's 'Taxonomy of Human Services' (Sales, 1991) 3) The USMARC standards for community information records being developed by libraries.

In terms of policy and planning, British CAB's participate in national policy development, develop and enforce standards and criteria, and cooperate extensively with other agencies to plan, evaluate, and accomplish research. In the U.S. there is no real national policy other than in the area of aging services, and seemingly little cooperative effort among I & R providers to develop standards and regulations. This is changing as AIRS members and others not only want to exchange information more readily to improve service delivery and cut administrative costs, but also because it is recognized that there will be federal pressure to regulate I & R activities in the areas of certification, standards of service, accessibility to services, quality of information and other significant issues. With the advent of the Americans With Disabilities Act, there will be further pressure to develop strategies that meet mandated requirements for accessibility as I & R organizations themselves find it necessary to accommodate their own operations.

'Disabilities Specific' Technology Information as Part of I & R

With the inception of the 'Tech Act, P.L. 100-407', it was recognized that there was a need for specific information about technology available to persons with disabilities to assist them in their individual circumstances, and that there were databases already developed that contained a wealth of information about technology items. These included Abledata (Hall, 1983) Open Access (Special Tech, 1990), and others.

Advances in technology are occurring at such a rapid rate that to catalogue and track what is available has become an immense task, as can be seen by anyone who has had the opportunity to access the Abledata database of over 17,000 product items currently. To access this information, and search it to find what is necessary, has become a major focus of 'Tech Act' programs across the nation, and this need to access and search for goods and services required that 'Tech Act' states develop some kind of formal information and referral function. This need to undertake I & R activities at the state level, and in some cases the regional or national level, has brought 'Tech Act' states into the fore as important I & R providers whose activities will have some bearing on the direction I & R networking will take in the U.S., particularly for programs that offer specialized services to persons with disabilities. The need to share a large, difficult to maintain database such as Abledata has been one major factor in driving decision making processes in the field. Greg Van DerHeiden's work at the TRACE Center in Madison, Wisconsin, using Mac computers and Hyper Card to develop a search engine for the Abledata database has been instrumental in making Mac's the micro-computer of choice for many programs, along with Apple's long investment in developing user friendly computers accessible to persons with disabilities, among others.

What has become apparent as this process has been undertaken is that information about the technology item, per se, is often insufficient (Juhn, 1990b). To access the technology, to be fitted

for it or learn to use it, to have sufficient money to buy it, even to be able to look at it prior to buying or to do 'comparison shopping' have all surfaced as problems that must be considered along with the locating of the appropriate technology, whether simple or very sophisticated. In this process it has been found that I & R is a key component. It has been found that those providing information about technology must network with others providing information about key services and goods not traditionally associated with specialized I & R functions. It has been found that as this networking has proceeded certain efficiencies of scale have become possible that can serve as integrating mechanisms for many service providers, regardless of program focus (Sugnet, 1988; Juhn, 1991).

What does 'the Tail Wagging the Dog' Have To Do With It?

The premise of this argument is that there is a great deal of money and talent concentrated in the area of 'disability specific' I & R activity. This convergence of talent and resource, along with a political climate that is mandating increased attention and services to people with disabilities, has in fact supported an infrastructure whose programs and choices may significantly impact I & R provision at all levels.

A very important area of concern relates to the 'RFP' process. Requests for proposals to develop specific programs is a very powerful tool in the hands of the research agencies who have money to spend. How the RFP is worded, what its focus is, how that

intent is to be operationalized and to what end the project must be directed are determined by who writes the request. NIDRR has traditionally been an extremely important player in the process of developing programs for people with disabilities, and has been involved in several different ways with projects specifically related to the provision of I & R. Education, Health and Human Services, and others at the Cabinet level also utilize RFP's to generate programs and conduit funding to developers. This paper proposes that RFP's that include I & R development as the major focus, or a significant component, consider including in their requirements that I & R development be consonant with any one of the recognized standards for I & R's. The aim is to reduce duplication, insure quality of materials for consumers, and simplify information sharing among those holding large information databases.

The other area of significant concern as I & R development occurs is the work being done at the TRACE Institute by Greg Van Derheiden. His Service Delivery Directory is a model for the nation, and the adoption of this program by the 'Tech Act' states could have major repercussions for the field of I & R. One of the major concerns is that federal monies have been used to develop a software that will be freely distributed nationwide that manages large service delivery information databases. This is a small market, but there are a number of companies providing this kind of software on a competitive basis. Van DerHeiden's entry into this field has implications for the marketplace, and even how large

information databases will be collected and formatted. Will this subsidized program be the way in which systems development occurs and is this an appropriate situation in a so called competitive marketplace?

Final Notes

The above two factors, i.e., the Service Delivery Directory available from TRACE, and RFP requirements from the Feds, are going to have a very significant impact at all levels in the field of I & R. They have already. It would be extremely wise if other major players in I & R such as libraries, United Way groups, software suppliers, and others were aware of the potential impact the above activities represent.

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ORGANIZING ASSISTIVE TECHNOLOGY INFORMATION CENTERS

Presented by:

Marian Hall, B.S., O.T.
Director
Adaptive Equipment Center
Newington Children's Hospital
Newington, CT

Organizing Assistive Technology Information Centers

Marian Hall
Newington Children's Hospital

Many new assistive technology information centers are being funded throughout the country. Developing these centers seems to be the next part of the information network that is needed to make information easily available to consumers. To do an effective job of developing the programs and managing the information flow however, there also needs to be some training for the new information providers in developing and maintaining these programs. This presentation obviously is not going to provide that training, but can point out some of the beginning steps of how to start a new information program.

Information and referral centers provide information to link individuals with needed services or provide answers to specific questions regarding available resources. Even specialized information centers on assistive technology require planning to define the basic scope and program goals, and this planning should ideally be done before staff is hired and the "doors are open," but it is never too late to revise and re-organize to solve operational problems that arise.

The five primary functions of information and referral centers are:

- resource file development;
- direct service;
- publicity;
- outreach; and
- planning.

Before defining the components of developing an information service it is important to define a target audience for the focus of the information services and that audience's needs. Particularly in today's economy, it is also important to fulfill information needs of individuals in the community that are not being met in any other way. This task may take a bit of research to really determine if no other information services exist on a particular topic: they may exist but they are not well marketed. In defining the needs that a center is to serve, it is critical that the organizers (and funding source) have a consensus about the specific needs, the goals for meeting these needs, and objective criteria to evaluate the outcome of the service to determine if the needs are being met.

As part of the initial research to determine what other services are in a community, and what the needs the new center should focus on, it is also important to identify barriers within the community. Examples of potential barriers include: lack of, or inaccurate knowledge of a service; resources that are not perceived as relevant; negative attitudes; and inadequate funds or transportation to use a service.

Organizing a Management Plan

Setting up a resource center will involve a great deal of detailed work and will require organization. No matter how small a program is, the five basic operations of management remain a constant. These operations are related and build upon one another, and time spent organizing here can help a program to succeed .

Established Management Techniques

Set Objectives

Objectives define the program's general purpose and philosophy, set quantitative goals, and establish priorities.

- Identify the program's purpose and audience
- Define the program's purpose
- Define the intended audience of the program
- Set measurable goals
- Prioritize goals

Get Organized

Analyze and classify work, dividing it into manageable activities.

- Analyze work needed to achieve objectives
- Decide who will do what when
- Develop good time management skills

Motivate and Communicate

Convey expectations clearly. Make a team out of those responsible for the work.

- Make staff aware of the general purpose and specific goals of the program
- Encourage staff contributions to the process of setting goals and priorities

Develop Measures

Establish yardsticks to measure performance.

- Evaluate progress towards goals on a regular basis to monitor deadline commitments
- Write down goals and keep records of activities

Develop Staff

Encourage self-improvement and expansion of skills; delegate responsibilities.

- Encourage continuing education through courses, workshops, etc.
- Encourage reading resource materials to update their knowledge base
- Encourage site visits to other related programs

Budget

Obviously the available operating budget for staff, basic fixed office expenses, supplies, etc. will dictate many of the previous issues. But it is important to do the planning process to determine if the goals are larger than the budget and then go back to the objectives and re-define them in line with the given budget. However, the initial planning exercise, even if it was way beyond the existing budget is a good process to help identify ideal vs. reality, and also to provide goals to work towards for program expansion.

Marketing

With an overall plan for what your program will do and whom you want to reach, it is time to produce a plan to build community recognition of the program. A marketing strategy will allow the task to be broken into manageable pieces. Once again, goals need to be set and the audience needs to be defined. Marketing goals have to do with defining consumer needs, producing a good product for those consumers, and getting it out to the consumer. It is important that the marketing efforts be in line with the general purposes of the program.

- List audiences.
- Which will use or need the program's services regularly?
- Which are in contact with frequent users?
- Which can help with funding, exposure, advocacy?
- Which will have information the program needs (i.e., manufacturers, vendors)?
- What are the larger markets and which will grow in the future?

Assess needs of those who need the service most and whether the program is meeting those needs. Check out the competition; avoid duplicating the efforts of other programs.

Know the Product

Knowing the product includes knowing what services are not offered. Recognize limitations of the program and don't make false promises. Distinctive competence in marketing theory says an organization should be exceptionally good at something in order to compete and survive. Focus on doing a few things well, and learn other good services in the community to use as referral sources for users.

Marketing Strategies

- Printed materials can include brochures, fact sheets, and form letters.
- Personal contacts and Networking, including speaking to groups, open houses, demonstrations at conferences, appearances on panels, etc.
- Publicity includes articles in newsletters or magazines, press releases, public service announcements and other media appearances.
- Advertising by purchasing ad space in newsletters and magazines.

Developing Program Resources

After defining the purpose of the program and the audience it is going to serve, the next step is to locate and collect the resources needed to provide information to users. Databases, directories and files are tools to help find information. But there should be a plan on what should be collected; with all the information available today it is easy to become overwhelmed trying to collect information on "everything."

There are two basic types of information most programs initially need to be concerned about: resources that provide direct answers to questions (e.g., what type of computer interface is available for a specific disability, where do I get it locally) and resources about other programs with specialty expertise. The goal is to become an expert within the planned scope of the program and everything possible needs to be identified and collected within that topic, and requests beyond the scope of the program should be referred to for other appropriate programs.

Organizing Information

There are many different filing systems and it is not important which type of system is used as long as it works for the staff in the program. However, filing systems are very time intensive to develop and set up so a lot of time should be spent in the planning stage. Future needs should be anticipated as much as possible to prevent the need to re-do all the files a year later because of the volume of materials available or new topics being added. Everything can be in one system, or several files can be used for different types of resources. A database may be desirable for organizing and retrieving data in the files, or even using it as an index to the files—but databases take an incredible amount of time to develop, and input and update data. This needs to be considered within the context of staff time and the budget, as well as overall priorities—where should limited staff time be used. But on the other hand, it doesn't help to have vast amounts of resource materials if no one can find anything to help answer users' requests.

A classification system of some type will be needed. Look at systems used by other programs. Most programs don't mind sharing a copy of their classification systems, or discussing how their files are organized. Talk with librarians. The simpler the system is the easier it will be to use and re-file information. Think through the problems that may occur and decide if what appears to be a simple time efficient solution (e.g., initially most people want to file product information by 'type of product' but this is complicated by the fact that most catalogs have many different types of products in the same catalog and then multiple copies of the information are needed for multiple product files—and all the multiple files need to updated).

Maintenance time needs to be scheduled for whatever file system is used. New information needs to be filed, and old information needs to be purged. Overstuffed files with out-of-date information are very difficult to use.

Processing Information Requests

Information specialists that are handling requests in an information center are the primary source of contact with the public. The information specialists are the information service from the user's point of view. User's contact an information service with a probl[illegible]'hey need solved. If the information specialist is helpful,

friendly and knowledgeable, the user will have a positive opinion of the service. If the information specialist conveys a bad mood or appears unknowledgeable of the information sources or how to use them the user will have a negative opinion of the service. One source states that a person with a good experience will tell four or five other people about it, but someone will tell nine or ten others about a poor service.

Non-profit or very small information services need to use the same techniques and practices of any business in operation for selling a product. In the case of information programs the product is information and there may or may not be a charge, but if the intent of the service is to stay in operation it needs to build a solid reputation for providing helpful, accurate and timely information within what it has defined as its scope of work. It must also provide more than just good service, the users must perceive that they are receiving good service. This means that even if users get an answer to their problems, if they were helped by someone who was less than friendly, or the user had to get pushy to get the needed information, they are not going to perceive that they got good service from the information program.

Qualities of Good Customer Service

- Courtesy
- Prompt attention and responsiveness
- Reliability
- Personal attention and empathy
- Knowledgeable staff

Organizing the Request Process

1. Develop a request form to obtain all data necessary to answer the request and statistical information required for the program's records.
2. Develop efficient record keeping procedures to keep monthly or weekly statistics.
3. Establish a timeframe for how long information requests should take. This can be used for measuring performance.
4. Decide how requests will be routed in the office. If there are several information specialists, they may specialize in topics, or separate quick answers from harder searches, etc.

5. Form letters, resource lists, and fact sheets may be developed for frequently asked sets of information. But remember that this information is constantly changing and these pre-packaged sets of information will also need to updated regularly.

In summary, developing an information program requires extensive planning and good information handling skills. Many standard business management skills can be transferred to even a very small operation, and information skills can be learned from other programs, literature, libraries, etc. Time is well spent doing detailed planning before actually opening a program for users. For a center to be successful it is important that the information specialists be concerned and aware of the quality information they are providing in response to requests. If users are routinely receiving poor quality responses from a center it doesn't take long for word-of-mouth to spread through a community, and it becomes extremely difficult to then overcome a poor reputation as an information provider.

IMPLEMENTING PL 99-457'S CHILDFIND COMPONENT WITH THE HELP OF ELECTRONIC DATA MANIPULATION

Presented by:

Coleman Poses, M.S.W.
Research & Information Analyst
Office of Mental Health/Mental Retardation
Philadelphia, PA

With the formulation of the final regulations for Part H of PL 99-457, Childfind has become operational. Among other things, Childfind is designed to assure that "(1) All infants and toddlers ... who are eligible for services ... are identified, located, and evaluated, and (2) an effective method is developed and implemented to determine which children are receiving needed early intervention services, and which children are not receiving those services." (Education and Handicapped Act Amendments of 1986). This paper considers one model of such a method; a model that examines where services are needed and where services are delivered. It prescribes reasonable dissemination of Childfind resources and gives special consideration to those areas where need is particularly intense. The study concentrates on Childfind in Philadelphia, PA., a city that contains over 1,700,000 people occupying 135,130 sq. miles (Bureau of the Census, 1990; Office of Mental Health and Mental Retardation [OMH/MR], 1989). Early Intervention clients are currently served through the Office of Mental Health/Mental Retardation. This agency manages 16 Early Intervention Programs in the City covering 25 different sites. There are currently 2,000 children served in the system (Office of Mental Health and Mental Retardation [OMH/MR], 1992). Philadelphia has been given considerable autonomy in making its own Childfind arrangements. As of this writing, however, Philadelphia has not received additional funding to carry out the Childfind mandate. The Early Intervention programs that Philadelphia currently funds are filled to capacity. A dilemma therefore occurs since many outside agencies, such as hospitals, DHS,and Lead Poisoning are reluctant to refer children through the County's Childfind because their clients would experience the frustration of waiting for early intervention services indefinitely; yet without these Childfind referrals, there is no hope that the County will get additional funding to serve the many children who reside within the Philadelphia's borders and who would be eligible for early intervention services. The intent of this paper is therefore to determine not only what the need is and where the need exists, but to outline a method to decide where and to what degree Childfind resources should be allocated.

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THE INDICES

Childfind can look at several different indices when considering where to center its activities. One index is the traditional prevalence of mental retardation model (Baroff, 1982), which considers mental retardation prevalence as a function of agelevel rates within a population. Another index considers the problems that a child may encounter at birth. These problems may be noticeable abnormalities at birth, problems with the delivery itself, or problems relating to the parent which would be likely to impinge upon the child (Blackman, 1986). Part H of PL 99-457 states that "States should consider tracking systems based on high risk conditions at birth." (Education and Handicapped Act Amendments of 1986). Yet another index might look at where services are delivered, the thinking here being that areas with a low level of services may reflect an untapped need. Another index might look at factors in the early years of life which may contribute to a diagnosed need for Early Intervention services. This index may show a cognitive, physical, or psychological need encountered by a practitioner through either a well baby visit or an EPSDT screening. Such factors would include lead levels in the blood greater than or equal to current Center for Disease Control (CDC) guidelines (Blackman, 1986).

With the use of these indices, and the supporting data, separate maps could be drawn of the city for each index specified. This study will limit itself to the first three indices since the data for the last index is unavailable to Philadelphia OMH/MR at this writing.

Three variables were therefore considered. The variables were: (1) Early intervention services delivered from July, 1990 to June, 1991, broken down by census tract; (2) The number of births occurring in 1989, by census tract; and (3) the number of problem births delivered in 1989 by census tract. Problem births are distinguished by any of a variety of physical factors such as low birth weight (below 1500 grams), birth injuries, complications of labor, 5 minute apgar score of 3 or less, complications of pregnancy, malformations at birth, and concurrent maternal illnesses; as well as social factors such as inadequate prenatal care, age of mother as less than 15 years,

education of mother as less than high school or the marital status of mother as unmarried (Blackman, 1986; Hoerlin, 1989).

THE CENSUS PROBLEM

In order to determine where the need of the younger population exists, this study relies heavily on the 0 - 1 population within census tracts. One is then faced with the problem of whether to use the Philadelphia Bureau of Vital Statistics data on births in the city as opposed to Census data for the 0 - 1 population. Before Robert Mossbacher resigned as Secretary of Commerce, he announced that the Census figures for 1990 would not be adjusted, even though it had been estimated that the census undercount nationwide may have been as high as 5.3 million people (PSDC News, 1991; Rapp, 1992) .

The preponderance of the undercount appeared to be most profound in major cities. Mossbacher argued that the only alternative to a house by house headcount was a statistical analysis of indirect data (PSDC News, 1991). Yet the data suggest that a city with the size and the complexity of Philadelphia would need at least a supplemental statistical analysis to determine its population in an unbiased fashion. In Philadelphia, a survival analysis conducted by the Office of Mental Health and Mental Retardation (OMH/MR) determined that at least 1,759,130 people live in the city currently (Department of Public Health, Office of Mental Health and Mental Retardation [OMH/MR], 1989; Okeke, Benner, Klugman, Poses, 1990), whereas the U.S. Census put the figure at 1,585,577 (Bureau of the Census, 1990). OMH/MR's figures were corroborated by the City Planning Commission by applying a standard occupancy rate (Philadelphia City Planning Commission, 1984) to the number of occupied residences in the city (Borowski, 1990). To understand the depth of this problem, the Census reported that the 0-1 population in Philadelphia in 1990 was 19,520. (Bureau of the Census, 1990) The Philadelphia Department of Public Health's data indicate that infants born to Philadelphia residents in 1989 numbered 28,841. (Philadelphia Department of Public Health, 1987). Even factors such as mortality and out-migration cannot account for such gross discrepancies in the data. The number of Infant deaths in 1989 came to 514. (Philadelphia Department of Public Health, 1989) Mass

outmigration from 1989 to 1990 seems unlikely because the loss of the city's labor force from the year 1989 to 1990 came to only 1.5% of 1989's figures (Department of labor and Industry, 1989 & 1991). In comparing births within census tracts from 1980 to 1989 (Philadelphia Department of Public Health, 1989) to the 0 - 1 population changes within census tracts from the 1980 to the 1990 U.S. Censuses, the U.S. Census reported decreases in 170 of the census tracts in which the Department of Health reported increases. Although the 0 to 1 population on the 1990 U.S. Census correlates highly with the birth data from the Department of Health (with a Pearson's R of .91) for the comparable period, the 0 - 1 population changes within census tracts from the 1980 to the 1990 U.S. Censuses correlate very low with the birth changes within census tracts from 1980 to 1989 (with a Pearson's R of only .09). (Bureau of the Census, 1990; Philadelphia City Planning Commission, 1984; Philadelphia Department of Public Health, 1980, 1989). Therefore, it is reasonable to conclude that for the purposes expressed in this paper, there will be a greater emphasis placed on the Department of Public Health's Bureau of Vital Statistics data than on Census Bureau data.

CUMULATIVE TOTALS

An effective method for reasonable Childfind outreach would be to examine those tracts with the highest numbers of births and problem births, and the percentages that they comprise in the city as a whole. In FIG 1, only 36 of the 365 census tracts in the city comprise 25% of all new births in the city. Only 89 tracts are responsible for 50% of the city's births, and only 163 (or 45% of all the) tracts are responsible for 75% of the births in the city. In FIG 2, only 31 of the all the census tracts in the city comprise 25% of all the problem births in the city. 79 tracts comprise 50% of the city's problem births, and 147 (or 40% of all the) tracts are responsible for 75% of the problem births in the city.

Although the greatest need is in areas with the lowest incomes and greatest proportion of minority population (Philadelphia City Planning Commission, 1984), these maps also present some very interesting new findings. For example, these

maps highlight a number of areas in Northeast Philadelphia which are comprised, primarily of white, middle and high income families (Philadelphia City Planning Commission, 1984). FIG 1, especially, targets this area of the Northeast by virtue of the number of births that occurs there.

Knowing that large pockets of need are concentrated in small areas of the city means that Childfind outreach resources can be allocated more efficiently.

INTENSITY AND RATES

Childfind outreach should be obligatory in those areas with the most intense need. Rates, such as the number of problem births per 1000 births, should give one an idea of how intense certain problems are in various parts of the city. Using rates in this fashion, however, can be very misleading because of the way that the census tracts are designed. "Census tracts" generally vary from "between 2,500 and 8,000 persons and when first delineated, are designed to be homogeneous with respect to population characteristics, economic status, and living conditions" (Bureau of the Census, 1990, p. A-5). Population shifts and large, sparsely populated areas such as city parks, piers, and industrial corridors, have made the comparison of census tract rates very difficult. As a result, an area with one problem birth of its ten newborns becomes equated with the area with 100 problem births of its 1000 newborns.

PERCENTAGE OF THE RANGE

Frequently, a large gap exists between a few census tracts with the most problem births, and the other census tracts under observation. For this reason, one method of judging intensity would be to divide the range of problem births (0 to 331) into 4 equal subranges (i.e. 0 - 82, 83 - 165, 166 - 248, and 249 - 331). The existence of only a few census tracts in the highest subrange of problem births would then indicate a certain need within those census tracts. The data substantiate this assumption. When the range of 331 is divided evenly into four equal subranges, (see FIG 3), only 6 tracts fall within the highest subrange of 249 to 331. The six tracts mentioned in this paragraph are all in North and West Philadelphia, areas which have the lowest per capita income in the city (Philadelphia City Planning Commission, 1984). FIG 4 indicates that there

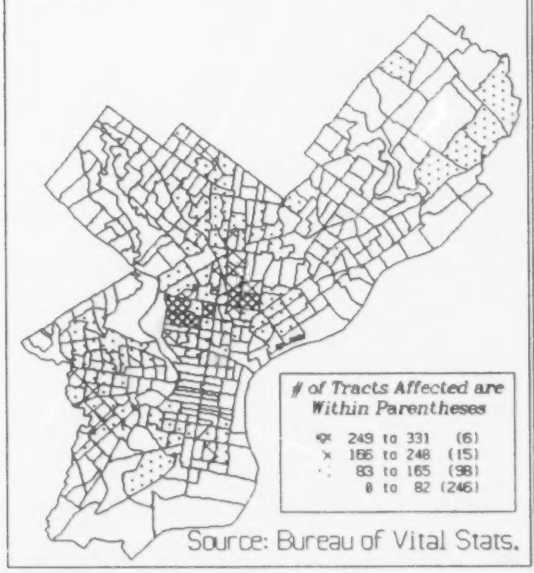
FIG 1:
TRACTS, SORTED BY # OF 0 - 1 POP. WITHIN TRACT, AND ATTENDANT CUMULATIVE PERCENTAGES, FOR 1989

Source: Bureau of Vital Stats

FIG 2:
TRACTS, SORTED BY 0 - 1 POPULATION WITH PROBLEMS WITHIN TRACT, AND ATTENDANT CUMULATIVE PERCENTAGES FOR 1989

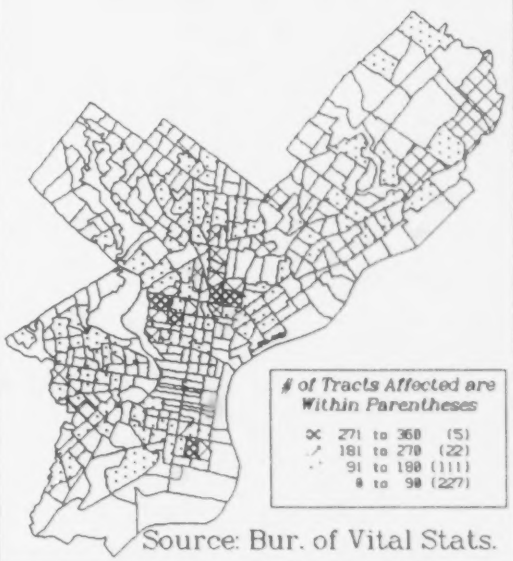
Source: Bureau of Vital Stats.

FIG 3:
0 - 1 POP. WITH PROBLEMS WITHIN CENSUS TRACT IN PHILADELPHIA IN 1989



Source: Bureau of Vital Stats.

FIG 4:
0 - 1 POP. WITHIN CENSUS TRACT IN PHILADELPHIA IN 1989



Source: Bur. of Vital Stats.

are only 5 census tracts whose birth frequency is in the top subrange of the number of newborns in 1989. Four of the five tracts overlap the tracts in the highest subrange of problem births.

RATES PER LAND AREA

Census tracts were originally created to contain the largest possible number of a homogeneous population (Bureau of the Census, 1990). As a result, census tracts themselves vary with regard to land area, and large census tracts many times contain parks or other relatively sparsely populated areas. Therefore, when rates are used, they should be based upon census tract land area to get a clearer idea of what the intensity of need is within a census tract. When rates are performed in this fashion, some of the larger census tracts in terms of land area have some of the lowest rates. Almost the entire Northeast region falls in the bottom quartile with regard to the number of problem births per live births per land area and this region falls within the third quartile now with regard to the number live births per sq. kilometer of census tract (Quartiles not shown).

When subranges are considered for problem births (FIG 5), six new tracts, half of which are in South Phila. become known to the city in this fashion. FIG 6 shows the number of births per sq kilometer broken up into subranges. Four additional tracts become known here. Altogether, seventeen tracts are highlighted as areas of concern. Three of these seventeen are distinguished as being in the upper range of the highest number of births and problem births as well as having the greatest number of births per land area of their census tract. These findings can be summarized as follows:

tract	# of births per census tract	# of problem births per census tract	# of births per sq kilometer of census tract	# of problem births per 1,000 live births per sq kilometer of census tract
6				X
21				X
22				X
31			X	
41	X			
128				X
130				X
148				X
151		X		
152	X	X	X	
164			X	
167		X	X	
169	X	X		
172			X	
175	X	X	X	
176	X	X	X	
198			X	

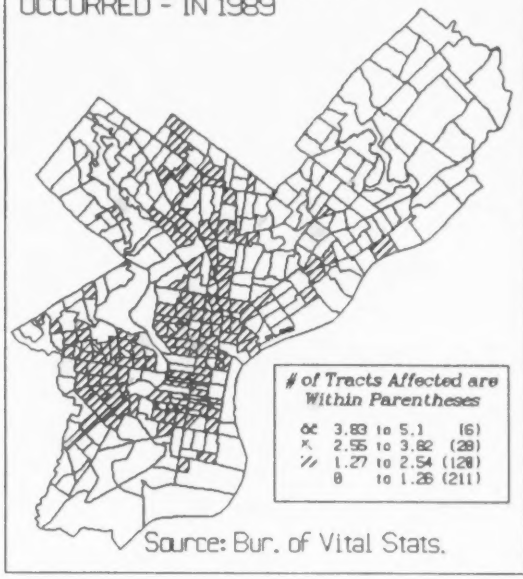
DIFFERENTIAL PROVISION OF SERVICES IN THE CITY

Although there appears to be a high correlation between the three exploratory maps, the correlation breakdown is as follows:

Births with Special Births - .9712
Births with Services - .7167
Special Births with Services - .6915

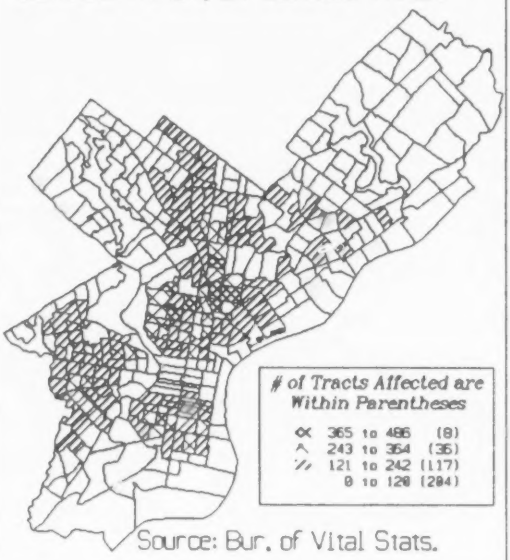
Even though the set of census tracts in the quartile of the highest number of births appears to coincide fairly well with the set of tracts in the quartile with the highest number of services (see FIG 7. Quartile maps for births and

FIG 5:
OF PROBLEM BIRTHS PER 1,000 LIVE BIRTHS, PER SQ. KILOMETER OF CENSUS TRACT IN WHICH THE BIRTHS OCCURRED - IN 1989



Source: Bur. of Vital Stats.

FIG 6:
NUMBER OF BIRTHS IN PHILA. IN 1989 PER SQ. KILOMETER OF CENSUS TRACT, BY CENSUS TRACT

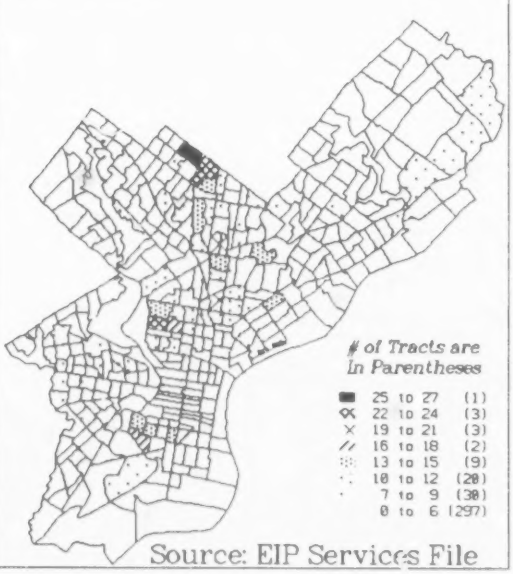


Source: Bur. of Vital Stats.

FIG 7:
OF CHILDREN RECEIVING EI SERVICES FROM JULY, 1990 TO JUNE 1991

Source: EIP Services File

FIG 8:
OF CHILDREN RECEIVING EI SERVICES, FROM JULY, 1990 TO JUNE, 1991



Source: EIP Services File

problem births are not shown), a correlation analysis of these two quartiles provides a Pearson's R of only .1245. In FIG 8, the range of the number of children receiving services is divided into eight subranges. Only two of the tracts in the upper four subranges of service match those tracts identified as having the greatest need. At least fifteen of the seventeen tracts of greatest need are therefore unserved or underserved.

LIMITATIONS TO THE STUDY:

Although this study relied to a greater degree on Philadelphia Department of Health's data over U.S. Census data, it did use census data in estimating the demographic composition of an area. Besides the issue of the U.S. Census data, there are other factors that limit the validity of the study's conclusions.

For example, many of the variables used in this study rely on the responses of mothers on a questionnaire. Items which could be potentially incriminating (such as items pertaining to substance abuse) have a high missing response rate.

There are also a number of problems that this study did not address. Child abuse and neglect, lead poisoning, data from well baby visits, and maternal PKU levels should be added to the list of problems that would establish Childfind need.

We also do not know what percentage of the group born with problems or a combination of problems would be eligible for services under the Federal and State guidelines. Currently, we do not have census tract information on 25% of our Early Intervention population. Philadelphia's new EI case management, tracking and record keeping procedures are expected to assure census tract information on 100% of Early Intervention clients, starting in July of 1992.

Finally, this study did not address the problem of Philadelphia's large homeless population. A screening in several homeless shelters of children who were 0 to 5 during the summer of 1989 concluded that a very high proportion of these youngsters should undergo a more definitive evaluation for developmental delays. Since the living arrangements of this group are so fluid, it would be nearly impossible to submit this group to the type of analysis presented in this

paper.

CONCLUSIONS AND RECOMMENDATIONS

This paper has outlined a method for Philadelphia where the attempt is being made to apply limited resources to Childfind activities. The method can be generalized to other major cities. The goal is to separate the area into subareas and to target those subareas where outstanding need surpasses the current early intervention services provided. The method may be outlined as follows:

(1) Separate the area into census tract.

(2) From the birth data provided by the local health department in a given year, identify those areas with the greatest number of births as well as the greatest number of births with various physical and social problems.

(a) Physical factors such as low birth weight, birth injuries, complications of labor, 5 minute apgar of 3 or less, complications of pregnancy, malformations at birth, and concurrent maternal illnesses were used in this study. Blood lead levels and PKU levels of mother should also be considered.

(b) Social factors such as inadequate prenatal care, age of mother as less than 15 years, education of mother as less than high school and the unmarried marital status of mother were used in this study. - Please note that another social factor not included in this study, but which should be considered, is information on child abuse and neglect on children 0 to 3, broken down by census tract.

(3) Look at the census tracts with the highest number of births and problem births. We've seen that in Philadelphia, 25% of all births and problem births are

concentrated in less than 10% of all census tracts.

(4) Along with (3), one must look at how services are distributed along census tract lines. Although in Philadelphia, services correlate moderately with births and problem births throughout all census tracts, the correlation was actually quite small between the quartile of census tracts containing the highest number of births and the quartile of census tracts containing the highest number of services, suggesting that there are some census tracts with both a high number of problems and a great need for early intervention services.

(5) There are a number of ways to arrive at those census tracts which have the greatest need; that is, where childfind outreach is necessary.

(a) Divide births, special births, and services into equal subranges. In the case of Philadelphia, only a few census tracts remained in the top subranges. It was also ascertained that the set of tracts with the highest number of births coincide with the set of tracts with the highest number of problem births, and that the set of tracts with the highest number of services excludes a large proportion of those tracts with the highest number of births and problem births. Five tracts had been identified as having the greatest number of births. Six tracts have the highest number of problem births. Four tracts with the highest number of births overlap the tracts with the highest number of problem births.

(b) Divide the number of births within a census tract by the area of that census tract and divide the number of problem births within a census tract by the

number of births within a census tract per land area of that census tract. Area of the census tract is available from the Census Bureau STF tapes. In Philadelphia, four of the eight tracts with the highest number of births within census tracts also have the highest ratio of births to land area of census tract. The ratio of the number of problem births to the number of births per land area reveals six new tracts that, when added to the eleven tracts mentioned previously, give a kernel of tracts where Childfind efforts are essential.

Ideally, Childfind's outreach efforts should perform optimally everywhere. In a large urban area with a heterogeneous population, and limited Childfind resources, that ideal may never be reached. This paper has therefore attempted to provide a realistic way of disseminating these services, while assuring that enforced efforts be concentrated in those areas of the most intense need.

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ASSISTIVE TECHNOLOGY TERMS AND CONCEPTS

Presented by:

Janie B. Scott, OTR/L
Program Administrator
Maryland Department of Health & Mental Hygiene
Baltimore, MD

Assistive Technology Terms and Concepts

Janie B. Scott, O.T.R./L.

The purpose of this paper is to introduce assistive technology to people with limited backgrounds in this area. The content of the module is based on the premise that decisions about assistive technology should be based on human functional requirements, such as walking, eating and communication. Consequently, people involved in providing assistive technology services should have an understanding of concepts related to human functioning. Such concepts include terminology and definitions, knowledge of the categories of human function, principles that should guide assistive technology practices, and the factors and their interrelationships that impact on the ability of people with disabilities to function in their environment.

To assist individuals in comprehending the impetus behind the sudden interest in assistive technology, the federal legislation related to persons with disabilities is briefly reviewed. The implications these laws have for the use of assistive technology are noted.

From 1973-1990 there were 17 important pieces of legislation which have impact on the lives of persons with disabilities. This legislation has already had, and will continue to have, an impact on the provision of assistive technology services.

Legislative Timeline for Access to Assistive Technology

1973 P.L. 93-112:	Rehabilitation Act (Section 504)
1976 P.L. 94-142:	Education for All Handicapped Children Act

1983 P.L. 98-221:	Rehabilitation Act Amendments
1983 P.L. 98-524:	Vocational Education Act
1986 P.L. 99-457:	Education of the Handicapped Amendment
1986 P.L. 99-506:	**Rehabilitation Act Amendments (Section 508)**
1986 P.L. 99-463:	Vocational Education Act
1987 P.L. 100-146:	Developmental Distance and Bill of Rights Act Amendments
1987 P.L. 100-360:	Medicaid Catastrophic Coverage Act
1988 P.L. 100-407:	**Technology-Related Assistance for Individuals with Disabilities Act**
1989 P.L. 101-238:	Medicaid Early and Periodic Screening, Diagnosis and Treatment Amendments
1990 P.L. 101-336:	**Americans with Disabilities Act (ADA)**
1990 P.L. 101-392:	Carl D.Perkins Vocational and Applied Technology Education Act
1990 P.L. 191-431:	Decoder Circuity Act
1990 P.L. 101-476:	**Education of the Handicapped Act Amendments (IDEA)**
1990 P.L. 101-508:	ADA Tax Credit

The items in bold will be discussed in detail. Note the distribution of laws over the years. The first important law related to persons with disabilities was passed in 1973 with the next law, P.L. 94-142, passed in 1976. Gradually, more laws were passed from 1983 to 1989. However in 1990, five laws were passed which directly impact the lives of persons with disabilities. It is apparent that the public has become more aware of the rights of individuals with disabilities during the past several years

and lawmakers are reacting to the pressure from persons with disabilities and the public.

Rehabilitation Act Amendments of 1986 represent the second set of amendments to the Rehabilitation Act of 1973. The original Rehabilitation Act provides basic civil rights protection to individuals with disabilities against discrimination in federal programs. Section 504 of the law also assures equal opportunities for children and youth with disabilities in schools receiving federal funds. The first amendments to the Rehabilitation Act were passed in 1983 and authorized several demonstration projects regarding the transition of youth with disabilities from school to work. The intent of the Amendments of 1986 was to recognize the critical role assistive technology could play in determining initial eligibility for rehabilitation services. Once the eligibility has been determined the provision of assistive technology can make job placement possible.

Some of the provisions of the Rehabilitation Act Amendments of 1986 are:

1. Recognized rehabilitation engineering as a service which included "...a range of services and devices which can supplement and enhance individual functions..." Worksite modifications, job redesign, and assistive devices and related services were also identified.

2. A requirement for state vocational rehabilitation agencies to describe how rehabilitation technology services will be provided.

3. Access to electronic office equipment-Section 508 was added at this time. Federally funded agencies must provide all workers (with or without disabilities) equal access to electronic office equipment. Employees with disabilities must be able to access and manipulate databases and applications to attain the same results as other workers.

Technology Related Assistance for Individuals with Disabilities Act of 1988 provides financial assistance to states through competitive grants to plan and implement a consumer responsive system of technology services for individuals of all ages with disabilities. The goal is to use the federal funds to initiate services that will eventually be assumed by the states and local resources.

Some of the major provisions of the of the Tech Act are:

1. Conduct a statewide needs assessment to determine the number of individuals who may benefit from assistive technology and related services.

2. Identify assistive technology resources and make the information available to the public.

3. Conduct public awareness activities to inform people about assistive technologies, their potential, and the services provided within their state.

4. Provide training to potential and current users of assistive technologies, as well as provide training and consultation to the professional community.

5. Support public and private partnerships to encourage the development and integration of policies to expand the availability of assistive devices and related services to individuals with disabilities.

Americans with Disabilities Act will protect approximately 43 million Americans with disabilities from discrimination in employment, public services, transportation, public accommodations, and telecommunications. Each title of the ADA specifically references assistive technology equipment or devices as a means to achieve access and equal opportunity.

Implications of the four major areas follow:

1. Employers may not discriminate against an individual with a disability in hiring or promotion. Once hired they must make reasonable provisions for job restructuring and accommodations for worksite modifications.

2. Public accommodations may not discriminate on the basis of disability, existing facilities must remove their physical barriers or provide alternatives to access, and all new construction and alterations must be accessible. Auxiliary aids and services must be provided to individuals with vision or hearing impairments or other individuals with disabilities, unless an undue burden would result.

3. New public transit buses, rail cars and bus and train stations must be accessible to individuals with disabilities. Public transit systems have to provide special transportation services to Individuals with disabilities who cannot use fixed bus services.

4. Companies offering telephone service to the general public must offer telephone relay services to individuals who use telecommunications devices for the deaf (TDD's) or similar devices.

Education of the Handicapped Act Amendments of 1990 P.L. 101-476 amends P.L. 94-142 which was passed in 1978. Among other mandates P.L. 94-142 made provisions for a free and appropriate education to all children ages 5 to 21. The second set of amendments of 1986 made provisions for services to children ages 3 to 5, established an infant toddler program, and provided services to families of infants and toddlers with disabilities. The amendments of 1990 have changed the name of the law to Individuals with Disabilities Act of 1990 (IDEA).

Some of the provisions of IDEA are:

1. Assistive technology services was added under the new definition of special education services which must be included in the students Individual Education Plan (IEP).

2. As stated by the Office of Special Education Programs, assistive technology cannot presumptively be denied by a school district to a student with a disability The need for assistive technology must be considered on a case by case basis in the development of each student's IEP.

3. Assistive technology can be special education or a related service (OT, PT, SLP, etc).

4. Assistive technology may be a form of supplementary aid or service utilized to facilitate a student's education in a regular education environment.

5. If participants on the IEP team determine that a student requires assistive technology in order to receive a free appropriate public education, and designate such assistive technology as either special education or a related service, then the services must be provided at no cost to the parents.

The terms assistive devices and related services were mentioned several times in the legislation, we will define these terms here.

Assistive technology (devices) range from no-tech to high tech. No-tech are items readily available within one's environment and can be employed to assist an individual with a disability. For example, a dog can be trained to detect snakes in a barn to assist and protect the farmer with a visual impairment. Low-tech devices are non-mechanical and non-electronic aids. They include splints, velcro, adapted feeding

utensils, bathroom safety equipment, ramps, etc. Relatively complicated mechanical devices, like wheelchairs are considered medium-tech. Electronic, and microprocessor based equipment compose the high-tech range of technologies. Applications of microcomputers, electronic communication aids and other sophisticated devices are examples in this category.

Assistive technology services are services offered by occupational therapists, physical therapists, speech language pathologists, rehabilitation engineers and others. Their services may be utilized to evaluate an individuals need for assistive technology, train the individual, their family, employer, or others in their support network in the use of the device. Fabrication, customization and repair of assistive technologies are included as a service. This area also encompasses large print for persons with visual impairments.

Assistive technology can provide persons with disabilities with numerous benefits. Materials, devices and services can assist people in learning in a classroom setting or at home. Assistive technologies can make doors, appliances and the environment in general more accessible. Some assistive technologies such as adapted computers and adapted work stations enable persons with disabilities to compete in the work place. Materials, devices and services can enhance the overall independence of persons with disabilities. As a result of utilizing assistive technology, the quality of life for persons with disabilities can be improved.

From the examples of assistive technologies just provided, note a very important fact: The purpose of each device just described was to improve someone's ability to function within the context of a particular environment. These assistive technologies enable people to respond to demands that are placed upon them by a particular environment that might affect them at any given point in time. For example, the school

environment may place a demand on a non-oral student to communicate. A communication aid may enhance the student's functional ability to respond to that demand.

It is also very important to note that assistive technologies are only one of many possible factors that influence the ways that people respond to environmental demands. Others include: external supports, such as rehabilitation, health services, and a variety of therapeutic interventions; and strengthening the person's ability to cope or adapt to environmental demands through education and counseling.

Seven functional categories have been identified to describe assistive technologies. The categories correspond to different functions that all of us perform. Understanding of these functions is particularly important for identification of assistive technologies, because assistive devices and services should be selected based on a functional approach. Examples of each of these categories follows:

The first category is **Existence.** Items in this category provide assistance in basic function areas needed to sustain life. Examples are hydraulic lift bathtubs, adapted potty chairs and other feeding, health care, and self care devices.

The next category, **Communication**, is comprehensive and contains items that facilitate the reception, internalization, and expression of information. Functions such as verbalization, tactile sensation, smell, sight, and taste are included in this category. Examples of devices which aid communication are talking clocks, optical head pointers, braille printers, and TDDs.

The third functional category is **Body Support, Alignment and Positioning**. These items stabilize, support or protect portions of the body that require them. Some examples in this category are a wrist splint, wheelchair supports, and leg braces.

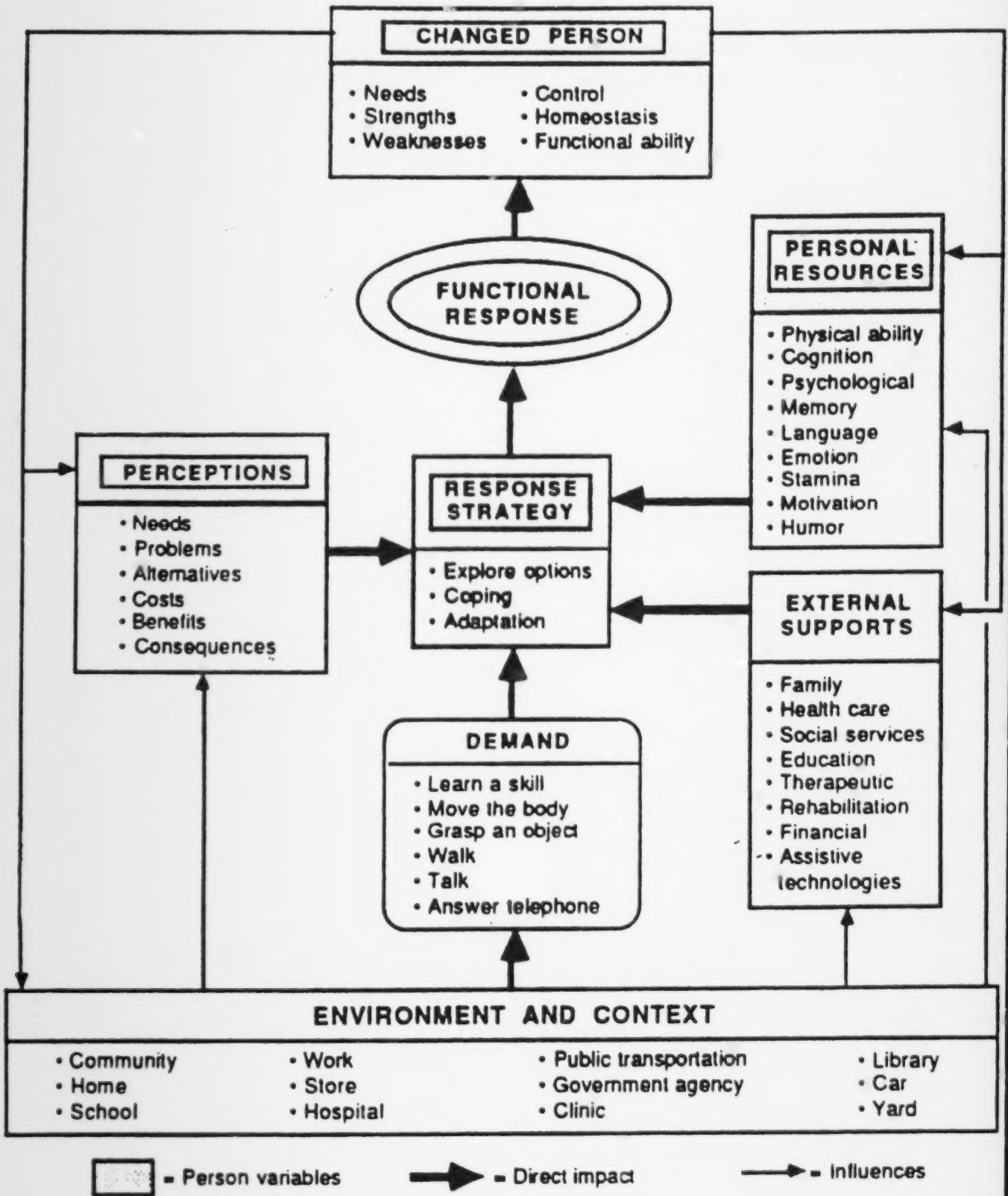
The fourth function addressed is **Mobility and Movement**. The devices found in this category help a person move about either horizontally or vertically. Examples include wheelchairs, devices for lateral transfer, and items used for vertical elevation. Canine companions fit into this category as they provide assistance and support to individuals with mobility and other impairments.

The fifth functional category is **Adaptation of the Environment**. Devices and accessories used to assist a person perform many of the activities involved in daily living are included here. Examples include adaptations for home skills, perceptual-motor skills and vocational activities. Vertical desks help individuals with low muscle tone to perform vocational activities, touch-activated lamps reduces ones needs to access wall switches, adapted cars and automatic door openers allow individuals to function more independently from home to work.

The sixth category includes items for **Learning, Education and Rehabilitation** in and out of the classroom and for therapy. Devices in the learning, education, and rehabilitation category include computer assisted instruction and interactive video programs. Devices in the rehabilitation category include those used for testing, exercising, training, and therapy.

The last functional category is **Sports, Leisure and Recreation**. Devices in this category enable people to engage in recreational and leisure activities. Some sample devices include: playing card holders, balls that emit audible beeps, adapted ski poles for one-legged skiers, and braille playing cards.

A Unifying Functional Model



Unifying Functional Model

The following information describes a model that provides a more complete context for considering human function and the factors that influence peoples' ability to function. Let's assume we have an elderly person whose home is located on a hill and who must travel down the hill to the mailbox to retrieve his mail. Let's call him Fred.

Environment and Context: The environment we are dealing with is Fred's home and immediate yard and sidewalk. The context is that Fred must retrieve his mail each day by walking to his mailbox. Let's assume that one day, Fred went to retrieve his mail in his usual fashion, but lost his balance and fell. Let's further assume that Fred's balance problem is not a transitory one, but one that is persisting.

Demand: The environment and context place many demands on all of us. In Fred's case, the environmental demand is to walk to the mailbox, open it, retrieve the mail, and return safely to his home.

Response Strategy: In preparing to make responses to environmental demands, people formulate a response strategy. Their response strategy may involve exploring a series of options that are available to them including using strategies for coping with the environmental demand or making adaptations that will enable them to respond in a constructive fashion to the demand. In Fred's case, he might explore options such as using a cane or a walker, petitioning the postal service to deliver his mail directly to his home, or having someone pick up his mail for him. In exploring options, he decides against a walker because of the danger of using such a device while attempting to go downhill.

Perceptions: A person's perceptions may play a big part in exploring response strategies and making a decision about which to accept. For example, some people may, or may not, perceive that a need exists or that they have a problem, such as when a

person with a hearing impairment refuses to wear a hearing aid. They may have perceptions about the desirability of alternative response strategies, such as the case of an adolescent who refuses to use a headstick because it draws what is perceived as negative attention from one's peers. People also have perceptions about the psychological, physical, and fiscal costs of different alternatives and their consequences. Fred realizes that he has a problem and acknowledges that he needs to arrive at a way to get his mail.

Personal Resources: A second factor in making decisions about response strategies relates to the personal resources that people have available to them. These relate to their abilities in areas such as physical functioning, understanding, speech and language, grip strength, motivation, and other factors of the person which can be used in producing actions. In surveying his personal resources, Fred believes that he has sufficient stamina and strength to physically travel to the mailbox, as opposed to having someone retrieve his mail for him. In addition, he has a fierce desire to be independent.

External Supports: A third factor influencing decisions are the external supports a person has available. Supports are resources available to assist individuals in responding to environmental demands. For example, family members can provide both emotional and physical support. Social service agencies can provide supportive services, such as instruction about ways to cope with environmental pressures. Health insurance agencies can sometimes provide financial support. Note that this is where our area of interest, assistive technology services, comes into play. In the area of external supports, Fred elects to try a cane and enlists a family member to obtain one for him at a local medical supply store.

Functional Response: The person's functional response is the result of the decision making in the areas that were just discussed. In Fred's case, the first response

was a walker that would have resulted in an unsafe trip to the mailbox. Fred's best response to the environmental demand was to use a cane to help him maintain his balance while retrieving the mail.

Changed Person: As a result of a functional response, the person is changed. The changes may be dramatic or subtle, depending upon the nature of the environmental demand, the decision making that was done, and the nature of the resources that were expended and the supports provided. Fred improved his ability to function in his environment by using a cane to assist him with mobility. He is now able to safely retrieve his mail, the availability of the cane has probably enhanced his mobility in other situations, as well.

This Unifying Functional Model recognize that some variables impact directly on various model components and activities. These impacts should have been quite apparent in the example with Fred. Components may be influenced, however the degree may vary. For instance, because Fred changed his ability to function, his perceptions have probably changed somewhat. He should be more confident in his ability to travel and his ability to be independent. Because of the availability of the cane, travel may be less tiring for him, thus enhancing his stamina. Similarly, family members may not need to provide as much external support for him.

When considering this model, one must remember that changes occur over time, can be constant, and the changes have the potential for impacting on the other components and subsequently on the functional responses made by the individual. The central focus of the model is upon the individual and the decisions that are involved in assisting that individual in responding to environmental demands. The functional model is a useful tool for helping to understand the factors that must be considered when providing assistive technology services. It helps us understand how a person functions, the factors that are

important in making decisions, and how the decisions that we make can impact on the individual.

The functional model has a number of implications for those who are involved in providing assistive technology services. The model identifies factors which should;d be considered in making decisions about assistive technologies. The factors identified in this paper are only a small portion of those that could impact on the individual. It illustrates interrelationships of factors and their potential for influencing each other. Although the model does not define causal relationships, it does help us to realize that many factors are involved and that they interact in complex ways. The model provides direction for those making referrals for assistive technology services. Individuals who make referrals should be encouraged to obtain as much information as possible about the various factors and provide data about them as part of the referral process.

Finally, the model can guide assessment activities for technology access. By attending to the factors in the model, and others that may be identified, those performing technology assessments can use the model to identify variables that should be evaluated for their potential impact on an individual. Assessments of those variables should generate data that can aid in making decisions about whether assistive technologies can help a person respond successfully to an environmental demand and the type of device or service that might be most beneficial.

Information for this paper was developed by Margaret B. Shuping, Jo Fleming, A. Edward Blackhurst and Joseph F. Melichar in the Department of Special Education at the University of Kentucky as part of a Special Training Project funded by the Office of Special Education Programs, U.S. Department of Education. This is one of several modules in a series known as the National Assistive Technology Training Series, or NATTS for short.

CASE MANAGEMENT & CLIENT TRACKING

Automation of Targeted Care Management

Presented by:

Deborah H. Coble, R.N., B.A., M.S.
Clinical Director

Steven Massey, A.A.
Director of Management Information Systems
Coordinating Center for Home and Community Care
Millersville, MD

AUTOMATION OF TARGETED CARE MANAGEMENT

What is the Coordinating Center for Home and Community Care?

The Coordinating Center for Home and Community Care, Inc. (CCHCC) is an independent care management organization. CCHCC has developed a comprehensive multidisciplinary care management system which facilitates the discharge of individuals with catastrophic illness from hospital to home. The CCHCC process combines clinically experienced professional managers with an advanced computer system to ensure cost savings and promote the highest quality of care for persons who are amongst the most expensive and complex to treat.

CCHCC is a manager of care, not a provider of care. Coordination of services by an independent impartial care manager provides the most cost efficient way to meet the optimal medical, therapeutic, and psychosocial development of the individual. CCHCC is able to objectively identify all necessary services and maintain neutrality while monitoring quality of care. The hallmark of this program is its ability to locate, coordinate, and monitor the quality, continuity, provision, and cost of services at home while avoiding conflict of interest.

CCHCC has developed a unique systematic approach to care management. Nothing is left to chance. The CCHCC system facilitates the move home for individuals who are at risk for long term or repeated hospitalizations at a substantial cost

to third party payers. This timely and safe discharge process provides a humane choice for families and a cost savings for funders.

Comprehensive predischarge planning is begun early in the hospital stay. CCHCC staff collaborate with hospital personnel in the discharge planning process. Detailed step-by step planning by care managers with direct experience in the clinical aspects of complex health care situations assures maximum benefits to payers and participants. Needs assessments, environmental assessments, and care plans identify resources, equipment, home architectural modifications, and levels of care needed to safely transition participants from the high cost in-patient setting to the home care alternative. Structured training in the specific needs of the individual help families become more comfortable accepting responsibility for their family member's care.

What about our Information Technology?

In an effort to expedite discharge planning and promote excellence in service delivery coordination for individuals with specialized health care needs, the Coordinating Center for Home and Community Care has designed a computerized model for professional providers. CCHCC's model is comprised of inter-relational tools which encompass the period from client referral to discharge.

These models are maintained in a database which allows

users to share information across multiple screens. The CCHCC computerized models have been developed to utilize time, resources, data and workers as maximally as possible while providing excellence and quality assurance of the care management product.

FACE SHEET & DISCHARGE READINESS INDICATOR PROFILE (DRIP)

The collection of data begins at the time of referral. The Face Sheet and the DRIP Sheet are two tools used by the Intake Coordinator to begin the collection of client specific data. At the time of referral, the Intake Coordinator will ask questions directly from the computer screen and input the responses. The Intake Coordinator creates a record by initiating a Face Sheet.

FACE SHEET

The Face Sheet (Figure 1) is divided into seven (7) parts. The data requested is general in nature and is data the hospital Discharge Coordinator is expected to have readily available.

* For whom & from where is referral made
* Client data
* Guardian data
* General data
* Insurance data
* General questions & comments

This data will help establish a functional profile for the client as well as identifying significant contacts.

DRIP SHEET

The primary focal point for targeted care management is the projected discharge date. Is the child medically stable? Is the child ready to go home? Is the home ready for the child? Is the family ready? The DRIP (Figure 2) sheet provides a framework which allows the coordinator to identify areas that need priority attention prior to discharge.

* Cost comparison
* Timing
* Environmental readiness
* Medical readiness
* Training

The questions asked generally prompt for yes/no or date entries. There are some questions that allow for freehand comments to be entered.

SERVICE DELIVERY SYSTEM

Due to the number of people involved in the process, the computer is used as a clearing house to document that a procedure has been completed. The Service Delivery System (SDS) (Figure 3) functions as an overall checklist and allows instant tracking of the status of a clients application/referral in our system. The SDS expands the two main periods prior to discharge into step by step tasks. The staff person completes the task and enters the date it was completed.

RESOURCE AND MEDICAL MANAGER

The Resource and Medical Manager (RMM) tool (Figure 4) serves two main purposes. First, it is a guide to parents and in home providers. The information on this report is a summary of the most requested information from the database.

* General client information
* Physicians information
* In home provider information
* Insurance information
* Utility information
* Emergency information

The second purpose is to provide CCHCC's support staff with a comprehensive directory regarding service providers for each child. This allows the staff to answer the general who, what, and where questions.

PLAN OF CARE

The Plan of Care (POC) is CCHCC's main working document. This document is the culmination of the total interdisciplinary team planning and input. This document serves several purposes. The two main purposes are: to provide the multidisciplinary team with a guide of client services and interventions, and to establish a cost effectiveness worksheet.

A team made up of parent, physician, insurance representative, agencies, vendors, and the representative from CCHCC is established for each child. The team convenes at designated points in the process. The POC specifically includes the amount, level and frequency of services and

interventions for the child.

* Nursing hours
* Therapies
* Pharmacies
* Nutritional plan
* Durable medical equipment
* Therapeutic equipment
* Disposable equipment
* Clinics
* Technology
* Transportation
* Anticipated Hospitalizations

The team will discuss these services and issues at the review meetings and make changes to adapt to the child's current needs. The team members sign the POC and copies are distributed to all team members.

When discussing home care as an alternative to inpatient hospitalizations, the cost effectiveness of care is an important factor to both public and private sector health programs. The POC is used to project the anticipated cost effectiveness of the home care plan. All items, from durable ventilators to disposable procedure gloves, are priced. There is also an inpatient care cost. The first year in home the actual cost during their hospitalization is used. The following years are estimated using current hospital rates. These two costs are compared to determine cost effectiveness.

FUTURE

CCHCC constantly strives to improve our care management product. We have recently adopted a team approach for service delivery and organizational process. New process and system ideas are initiated, refined, and evaluated prior to

integration into the computerized system.

Currently, the Center is examining a team tracking tool for monitoring the first two (2) years of home care following initial discharge. This model is intended to facilitate team efficiency within established process and also allows for continuous utilization review of operational and team performance.

FACE SHEET

KEY: 999

FIGURE 1

Referral Date:

Status:

Referred by :

Phone:

Present location:

CLIENT INFORMATION

NAME

Social Security #

Address:

M/F:

DOB:

Diagnosis

Technology

GUARDIANSHIP INFORMATION

Phone

Mother's Name:
Address:

HM:
WK:

Father's Name:
Address:

HM:
WK:

Parent or Legal Guardian
Name:

HM:
WK:

GENERAL INFORMATION

Physician:

WK:

Dates of written release of information
From To

Billing Cycle:

@CCHCC, Inc.

FACE SHEET

FUNDING INFORMATION

MEDICAID INSURANCE

M. A. #: Expiration Date:

PRIVATE INSURANCE 1

Insurance Company: Expires:

Policy #: Group # :

Contact : Phone:

PRIVATE INSURANCE 2

Insurance Company: Expires:

Policy #: Group # :

Contact : Phone:

QUESTIONS

If in the hospital - Who is the person responsible for the discharge coordination? :

Have the parents been informed? (YES/NO) :

Have the parents consented? (YES/NO) :

If yes - What date? :

Have the parents applied for SSI for child :

If yes - What date? :

COMMENTS

FIGURE 2

DRIP SHEET

KEY: 999 ,
Name

COST COMPARISON READINESS

Has the financial obligation to the state of Maryland been identified: :

TIMING

What is the targeted discharge date? :

Is there a transfer planned or possible to another facility prior to discharge? :

What is the reason for transfer? :

When will this transfer be completed? :

ENVIRONMENTAL READINESS

Is the family residing in the discharge residence? :
Comments :
:

Are there any building or environmental changes necessary or planned prior to discharge? :
Comments :
:

Are the phone, elect. & plumb. services in place? :

Are any of those services at risk of termination? :
Comments :
:

@ CCHCC, Inc.
10/91

DRIP SHEET

MEDICAL READINESS

Are there any planned procedures or evaluations prior to discharge? :

What are these procedures? :

When will they be completed? :

Is the discharge technology in place at home? :
Comments :
:

Is the child stable on this technology? (72 hours) :
Comments :
:

TRAINING

What is the current status of training for:

Family caregivers (primary and backup)?
:
:

Primary nursing agency?
:
:

Back-up nursing agency?
:
:

BEST COPY AVAILABLE

FIGURE 3

CCHCC SERVICE DELIVERY SYSTEM

KEY 999

Client name : ,

I. Intake procedure

Initiate and complete FACE Sheet	FSS :
Request DHMH 3871-B from specialty Physician (if 3871 received prior to intake, obtain FACE Sheet	FSS :
Release of information to family	FSS :
(If not returned in 2 weeks, follow up, re-send if necessary	AA :
Insurance Survey	FSS :
Copy of Face Sheet to FSC to schedule Exploratory Meeting	FSS :
Exploratory Meeting - date scheduled	FSC :
Obtain: Medical Assistance Application	FSC :
Needs Assessment - Part I	FSC :
(As applicable)	
Financial Survey	FSC :
Environmental Survey	FSC :
Exploratory Meeting - date held	FSC/FSS :
Exploratory Minutes	FSC/FSS :
Distribute to: C3	AA :
Family	AA :
Referral	AA :
DHMH - 3871-B received/logged	AA :
(Give to FSS if no Face Sheet)	AA :
DHMH - 3871-B to Clinical Director	AA :
Review and sign	CD :
Assign Clinical Care Coordinator	CD :
Assign Waiver program	CD :
Submit to AA to mail to Delmarva	CD :
DHMH - 3871-B to:	
Clinical Care Coordinator	AA :
Educational Coordinator	AA :
FSC	AA :
Holding File	AA :
DHMH - 3871-B Original to Delmarva	AA :
DHMH - 3871-B returned/certified	AA :
Any ineligible determination -	
Notify Clinical Director	AA :
Original in Holding File	AA :
Copy to Financial Manager	AA :

Any information held in holding file prior to active file status.

If holding file contains release, Face Sheet, and certified DHMH 3871, the file becomes active	AA :
Active file to Financial Manager	AA :
Financial Manager enters file in data base	FM :
Active file initiated/book made	AA :
Medical Assistance Application received	AA :
Application to FSC	AA :
Application Reviewed	FSC :
Application sent to Dept. Human Resources	AA :
Application returned/ Determination made / to FSC	AA :
Original application in file	AA :
Pre-discharge meeting scheduled for	C3 :

I. DISCHARGE PROCESS

Predischarge Meeting Request Form to AA	C3 :
Schedule Predischarge Meeting	AA/C3 :
Convene Predischarge Meeting	C3 :
Draft Plan of Care	C3 :
Confirm interdisciplinary team members	C3 :
Speciality Physician	C3 :
Notify C.M.S	C3 :
Disposable/durable/respiratory Euipment Vendor	C3 :
Theraputic/Adoptive Equipment Provider	Ed.C. :
Nursing Care Provider (Primary)	C3 :
Nursing Care Provider (Secondary)	C3 :
Independant Nursing Care Providers	C3 :
Community Pharmacy	C3 :
Community Therapy Provider	Ed. C.:
Local Eductional Agency (LEA)	Ed. C.:
Local Health Department	AA :
Notification Letters	AA :
Notification Letters - C3 initial	C3 :
Complete Predischarge Meeting Minutes	C3 :
Submit Minutes to AA	C3 :
Distribute Minutes	AA :
Initiate Resources and Medical Managers form and submit to ADministrative Assistant	C3 :
Complete Resources and Medical Managers form	AA :
Review completed Resource & Med. Managers form	C3 :
Initiate and mail Emergency Letters	AA :
Gas and Electric Company	AA :
Telephone Co.	AA :
Public Works	AA :
Local Rescue Squad	AA :
Fire Department	AA :

Determine Cost Effectiveness	FC :
Predischarge Home Visit	C3 :
Submit Discharge Meeting Request form to AA	C3 :
Schedule Discharge Meeting	AA/C3 :
Convene Discharge Meeting	C3 :
Finalize Plan of Care	C3 :
Documentation of first two weeks post discharge nursing care schedule	C3 :
Obtain nursing care plan	C3 :
Confirm availability of prescriptions	C3 :
Confirm referral for therapy/educational services	Ed. C.:
Submit/confirm adaptive/theraputic equipment order	Ed. C.:
(1231 as appropriate)	Ed. C.:
Skills checklist (as required)	C3 :
Physicians orders for discharge	C3 :
Physician emergency and notification protocol	C3 :
Obtain signature for the Plan of Care	C3 :
Obtain signature of C.M.S. Physician on POC	C3 :
Plan of Care returned to CCHCC	C3 :
Obtain Medical Discharge Summary	C3 :
Obtain Medical Discharge Summary	C3 :
Obtain Social Discharge Summary (as available)	FSS :
Distribution form (Plan of Care) completed	C3 :
Complete discharge meeting minutes	C3 :
Submit distribution form and minutes to AA	C3 :
Mail distribution packets to team	AA :

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FIGURE 4

C.C.H.C.C
8258 Veterans Highway Suite 13
Millersville, MD 21108
(301)987-1048 (301)621-7830

Coordinator:

Date of Update:
Entered by:

Name: ,

Phone: (H)
(W)

,

Parent/Legal Rep:

MA#:

Pricipal Physician:
Address:

Phone:
Ext.:

Community Physician:
Address:

Phone:
Ext.:

*** Nursing Agency (limit 2) *** ** Contact ** ** Phone **
(1)
(2)

*** Vendor Name (limit 3) *** ** Contact ** ** Phone **

*** Education Facility *** ** Contact ** ** Phone **

*** Private Insurance Company *** ** Policy # ** ** Phone **
(1)
(2)

Gas & Electric Co.:
Telephone #:

Telephone Company:
Telephone #:

Fire Department:
Telephone #: 911

*** Other Providers ***

Pharmacy:
Nearest
Cross Street:

Number:

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DEVELOPMENT OF AN AGENCY-WIDE PLAN TO ESTABLISH AN ELECTRONIC COMMUNICATION SYSTEM AND BETTER INTEGRATE INFORMATION TECHNOLOGY

Presented by:

Isaac Joyner, M.P.H.
Planner
South Carolina Continuum of Care
Columbia, SC

SUMMARY

From its inception in 1983, the Continuum of Care has grown in both size and scope, and has been maturing in its ability to coordinate and provide effective treatment services for an increasing number of the severely emotionally disturbed children (SED) and adolescents in this state. It has been estimated there are at least 600 SED youths, twice as many as are now served, in this state eligible for service. The longer-range goal is to enhance agency capabilities to be able to serve all those SED youths who meet the criteria for services of the Continuum of Care.

While certainly a challenge, these goals are not unrealistic. But reaching these goals in light of these tough economic conditions, has drawn the concern of the agency's management. Three approaches are plausible: (1) incrementally hire staff to match corresponding increases in the number of clients served; (2) acknowledge that adding new FTE positions in these hard times is unrealistic, and therefore, lower the agency's goals; or (3) take steps to make the existing and future staff more efficient and effective. The first scenario is ideal; the second is likely—if the third scenario is not aggressively pursued. This document addresses the latter direction, from an information technology perspective.

In a review of concerns, a major issue cited by the agency's management is the convenient and timely electronic access, statewide, to quality client information. For example, SED youths historically require immediate treatment resulting from erratic and sudden behavior. In response, case managers must secure the necessary client-related information to make required treatment modifications, as warranted. Agency management is also concerned about the quality of client data to the extent that the computerized data must be accurate, for obvious reasons. Two additional concerns relate to the need throughout the agency for modern information technologies, (PCs and a network), and the reaction of staff to the introduction of these technologies into their workplaces.

To address these concerns and move toward their resolution, an external consultant's review of the agency was initiated. The review initially focused on network concerns through the assessment of the methods used by staff to transfer information statewide, and the frequency and amount of information transferred. The outcome of this process reaffirmed management's initial conclusion that information is not easily accessible and that, indeed, there was a need for a statewide agency network. Moreover, the study revealed the following:

- Agency staff are not properly trained to take advantage of modern/powerful information technologies.

- An abundance of client and related information is available in the agency's computers. However, technologies, policies, and guidelines required to optimally integrate, analyze, summarize, and publish this information are virtually non-existent.

- A well-developed information Technology infrastructure does not exist within the agency.
- Operational information technology issues are generally dealt with in a piecemeal/unstructured manner.
- Agency goals are in jeopardy unless "the proper use and management of modern and sophisticated information technologies is viewed as mission-critical."

These study findings suggest the agency is not yet ready to support and make efficient and effective use of the investment in a sophisticated communications network, as previously envisioned. Rather, a two-pronged, four-phased approach has been developed for the agency. The two prongs address: (a) preparing management for the agency's introduction and use of modern information technologies (i.e., an Information Technology Strategy), and (b) implementing agencywide communication-enabling technologies (i.e., Multiple and Simultaneous Networking Solutions).

The four phases include: (1) Information Technology Awareness and Education; (2) Departmental Task Automation; (3) On-line/Remote Access Automation; and (4) Universal/Integrated Continuum System Implementation. Activities integral to each phase should result in a *continuum of knowledge and accessibility* of information and information technologies. The following recommendations are suggested for adoption and implementation to enable the agency to realize its return on future information technology investments:

- Establish and publish *Vision and Direction Statements* thereby: (a) demonstrating a top-down commitment by management to a new statewide information technology focus and (b) providing a *Roadmap to the Future* for agency personnel to follow.
- Establish forums to introduce and review information technology-related issues and projects.
- Position staff to optimally use information technologies toward the realization of the agency's visions and goals.
- Maximize the agency's return on its information technology investments through the simultaneous implementation of multiple networking solutions.

Management and staff of the Continuum of Care, through the adoption and implementation of these information technology management tools, will be equipped to begin to resolve the major agency concern which is to provide convenient and timely electronic access, statewide, to quality client information. Through the fulfillment of this particular objective—one of the essential ingredients to realizing the agency's vision—the Continuum of Care will be positioning itself to more effectively serve an increasing number of the severely emotionally disturbed youths of South Carolina.

ORGANIZATION, PRIMARY RESPONSIBILITY, AND INFORMATION TECHNOLOGY ENVIRONMENT

From an information technology perspective, the Continuum of Care currently maintains a client information data base in its CIS (Client Information System) unit located in the State Office in Columbia. Client and related data bases supported by the CIS staff include: client application and selection information, client treatment activities, Medicaid service billing information, and related support information. This information is directly accessible to staff located within the State Office building through a technology called a Local Area Network (LAN). Within this environment, staff with personal computers (PCs) connected to the LAN have on-line access to the client information. Staff located in the Regional Offices throughout the state, however, are not able to electronically access this information.

THE STUDY PROCESS

The agency study focused on information technology and related issues. The study collected information regarding the extent of the current information technology environment to assess the agency's ability to properly use and manage modern information technologies. The study focused on the collection and analysis of information and its flow among the various divisions of the State Office and the Regional Offices. During the study, an emphasis was placed on the detection of possible patterns and trends to help quantify the information *traffic loads* (volumes and frequencies of information exchanges) among offices statewide. Historically, quantifying the traffic levels produces meaningful and appropriate recommendations toward the ultimate selection criteria for equipment purchase and implementation.

The study process included interviews with management and key staff of the State Office and the Regional Offices. Topics included the functional, technical and organizational aspects of individuals' job roles, responsibilities, and concerns as they related to the need for, and use of, client information and information technologies.

In addition to the interviews, mini-surveys and summary charts were developed in an effort to obtain information regarding the quantifiable aspects of information exchanges within the agency and the impact these quantities are likely to have on proposed technical solutions. Through these mechanisms, the agency's use of its: (a) long-distance telephone service, (b) various mail services, and (c) facsimile device located in the State Office in Columbia were analyzed.

THE RESULTS OF THE STUDY

Observation: Client and Related Information Are Integral to the Agency's Mission

Severely emotionally disturbed youths are subject to sudden and erratic behavioral changes requiring immediate attention and resolution by case managers. It is fundamental and essential that case managers be provided with the required information to expedite frequent relocations and/or changes in individual client therapeutic treatment activities and placement.

Observation: The Characteristics And Needs of Regional Offices Vary

The Regional Offices vary considerably in location, size, and available support resources. Most of these offices have several full-time staff members to provide the appropriate client and support services. A few offices, however, are limited in the number of employees available as these serve a small, localized SED client population.

In general, organizations with geographically dispersed offices and field personnel, such as the Continuum of Care, encounter difficult management and logistical issues relative to the dissemination of information. The Continuum of Care is no exception in this regard as the process of sending and receiving necessary information throughout the state is cumbersome, slow and, at times, costly. The State Office in Columbia requires information from the Regional Offices for the State Office to be able to prepare necessary summary-reporting client and agency information to the Board, the General Assembly, the Governor and to the federal government. Regional Offices, on the other hand, require information relative to case management issues but must also accommodate State Office reporting requirements.

The capabilities and ages of information technologies installed within the Regional Offices to carry out these responsibilities varies as does the number of installed technologies. These numbers, in fact, vary from "very little, to borrowed, to personally-owned, to none." In this Information Age where employees are now accustomed to using computers in their workplaces, there is a lack of computer resources for staff within the agency's Regional Offices.

Observation: Operationally, Agency Programs are Dynamic

As the Continuum of Care seeks to provide the most effective care and treatment programs and services to the SED youths of this state, agency programs and operational practices must be flexible and adaptable. The Continuum of Care is required to constantly react to, and resolve, the frequent and sudden changes in behavior and treatment responses of its clients. These changes necessitate, in most cases, immediate alterations in client treatment programs—previously deemed appropriate.

Operationally, then, the agency must move quickly when these incidents occur. Case managers and the agency administrative support staff as well as agency processes must be flexible to facilitate immediate availability of new and/or additional provider services. Not coincidentally, current client information must be retrieved quickly to provide the necessary support information to initiate the procurement of alternative services from providers. In some instances, existing service contracts with providers must be altered; in others, new contracts must be immediately developed and services procured. The ability of staff throughout the agency to expedite these activities is crucial.

Observation: High Administrative Workloads of Case Managers Are Of Concern

Case managers in the Regional Offices are required to facilitate treatment planning, procure services and visit their clients periodically depending upon the severity of those clients being served. These activities result in the mandatory recording of detailed information regarding:

- the particular service activities administered
- case manager observations on client progress in recommended treatment, and
- the duration of each visit.

Observation: A Consistent and Positive View of the Value of Information Technologies Is Lacking among Agency Management and Staff

Those organizations placing a high reliance on information technologies to achieve agency program and administrative goals are not using a unique, untested approach or strategy. Case studies of businesses and state agencies indicate positive results from the incorporation and integration of information technology strategies, policies, guidelines, and equipment into the organization's processes and systems. From the interviews with management of the Continuum of Care, a *common* and positive attitude and awareness of the potential value and role of information technologies does not exist. The fallout of this view is a disjointed, internal approach to the use and management of information technologies as these are used to assist the agency in achieving its goals and mission.

SPECIFIC INFORMATION TECHNOLOGY-RELATED FINDINGS

Specific Information Technology Findings follow, each of which was developed through the analysis of the data collected from the study process. These study findings and recommendations are described using a model in the form of a series of questions. The model then asks the following questions:

- *what* are the major issues and problems,
- *why* are these issues and problems?
- *how* might information technologies help resolve these issues and problems? and lastly,
- *when* might these information technology solutions be implemented?

The following findings describe the *what and why* issues of the model and are conceptually grouped in two areas: Information Technology Management Planning, and Information Technology Utilization. The former addresses the information technology organizational, procedural and policy issues applicable to the Continuum of Care; the latter focuses on information technology operation and implementation issues. The other component of the model, (addressing the *how*, *what* and *when* information technology issues) is described later in the section on Recommendations from the Study Findings.

Finding: Information Is Not Easily Accessible

As described earlier in this document, information is critical to the effectiveness of the SED client treatment programs provided through the Continuum of Care. Sudden and sometimes violent changes in SED youth behavior requires immediate resolution. The ability of case managers to facilitate appropriate and immediate actions is highly dependent upon their ability to have timely access to the appropriate client information.

The sources for information required by case managers and support staff are numerous. Externally, these sources range from physicians to service providers to other state agencies. Regional Office staff currently do not have the appropriate information technologies to gain access to the required client information from these sources.

Finding: Agency Staff Are Not Properly Trained to Take Advantage of Modern/Powerful Information Technologies

Recently, the Continuum of Care planned to purchase and implement: a sophisticated communications network; powerful personal computers with modern, functionally-rich user software; and PC-integrated facsimile capabilities. The intention of this strategy was to improve the ability of agency staff around the state to have on-line, electronic access to client information in the State Office's CIS system and to provide staff the computer tools for them to begin to automate tasks within their offices.

These goals do address the very critical need of agency staff to have better access to information. However, few within the agency have been trained or have sufficient computer experience at this time in the proper use of these proposed powerful and complex technologies. Without question, Regional Offices desperately need a basic set of modern information technologies with powerful features. However, without specific personal computer training *prior to actual on-the-job use*, the purchased equipment will likely be greatly under-utilized. Moreover, and under these circumstances, the technical staff in the State Office will be pressed to provide technical service and user software support to an

untrained/unskilled set of remotely-located users—a difficult, costly and time-consuming task. Many staff within the Regional Offices, in particular, must begin to acquire the basic computer skills (in DOS and specific user applications software, such as word processing, spreadsheets, data base management, etc.) necessary to be (a) productive, (b) efficient, and (c) independent problem-solvers. These are skills that typically emerge through proper use training.

Finding: An Abundance of Client and Related Information is Available in the Agency's Computers. However, Technologies, Policies and Guidelines Required to Optimally Integrate, Analyze, Summarize and Publish This Information Are Virtually Non-Existent

The Agency's CIS system is the computer repository for several agency applications and client information. The major applications and data bases include: Client Application Eligibility, Client Application Scoring, Client Intake, Monthly Services Provided Report, Case Management Information, Update Client Information, and Case Closure Information. In addition to these, the CIS system maintains information regarding its: Service Development Plan, Internal State Information Technology Plan, Total Service Plan, and Medicaid Billing, among many others. Other data bases such as the Provider Contracts and Procurement applications are located in stand-alone PCs in the Administrative Services Building in Columbia.

Generally, the use of computers to produce quality and accurate reports (as examples), especially for the untrained and the newly-trained, is typically an extremely time-consuming process. Computer users within the Continuum currently lack preparatory computer policies, guidelines and training and, therefore, are susceptible to unknown hazards inherent in computer use. For example, management of the filing of computer documents can be a very difficult and, at times, wasteful task for the untrained/ unskilled computer user. The proper document *naming conventions* and filing procedures must be learned. Moreover, for staff—particularly managers—a tendency will be to improperly budget their computer time with their other work priorities. Well thought-out PC user policies and guidelines are not only helpful but are essential.

Finding: A Well-Developed Information Technology Infrastructure Does Not Exist within the Agency

An Information Technology Infrastructure, as applied to a multi-location agency, is described as: the presence of modern hardware and functionally-rich software; trained users; on-line/remote access; remote-location technical support; and appropriate information technology planning-and-accountability policies, guidelines, and practices. An infrastructure, as described, enables organizational *effectiveness* while pursuing operational *efficiency*. While important, efficiency can be viewed as a measure of the speed and ease with which an agency functions. A truer judge of the value of an agency lies in the

usefulness of its services to its intended client base and whether its services are used by these clients. In essence, efficiency is a means to an end, and not the end itself.

What has not been addressed is the issue of what is required for the agency *to plan for and manage a modern information technology environment* and how to make that overall environment a common, essential and effective component in the process of delivering agency services. Simply defining and installing information technology solutions will not work. Simply reacting to user requests for information technologies will not work. What is first needed is the development of, and continued adherence to, an agency information technology strategic planning and management framework, or model.

Finding: Operational Information Technology Issues Are Generally Dealt with in a Piecemeal/ Unstructured Manner

From an organizational perspective, new information technologies (both equipment and automated software systems) are often introduced into the Continuum of Care in an informal manner. While a formal Annual Project Review process does exist, it is not utilized with any consistency for information technology projects. Moreover, planning decisions regarding related information technologies (e.g., computers, telephones/lines, and reproduction technologies) are dealt with, in general, from an independent division perspective. For example, the responsibility for telephone systems/stations/lines falls within the Administrative Services Division; whereas planning for remote-user computer access and PC-based facsimile capabilities are the responsibility of the Planning and Development Division. These computer-based capabilities use similar technologies (ordinary telephone lines); however, agency planning decisions are often organizationally independent.

Finding: Agency Goals Are in Jeopardy Unless "The Proper Use and Management of Modern and Sophisticated Information Technologies throughout the Agency Is Viewed as Mission-Critical"

For managers, technology planners and implementers this means that a continuous review of the latest technology solutions is essential. It is sound management practice to be continually aware of new cost-effective solutions and to be prepared to adjust planning solutions, where appropriate, and on relatively short notice.

The agency's goals, as described earlier in this document, have sweeping impacts on the staff of the agency who have the responsibility to achieve the goals. When viewed from a common-denominator aspect, (i.e., information technology), the success of these goals depends upon effectively planning and efficient use of information technologies. The following are appropriate questions to ask

regarding this claim of the criticality of modern information technologies to the agency's mission and goals:

- Would the goals be achievable by simply adding more people?
- Would the information technologies used by the agency today allow it to reach its stated goals?

RECOMMENDATIONS FROM THE STUDY FINDINGS

Recommendation: Establish and Publish *Vision and Direction Statements* thereby: (a) Demonstrating a Top-Down Commitment by Management to a New Statewide Information Technology Focus and (b) Providing a *Roadmap to the Future* for Agency Personnel to Follow.

The key component of an information technology infrastructure and the prerequisite to information technology projects and purchases, in general, is a declaration of a *Vision and Direction* statement by agency executive management. As agency staff and managers plan for and implement department-based projects, there is a need for these people to know how these projects fit into the overall direction of the agency. Whereas agency management is currently developing several new goals, generally addressing organizational and programmatic issues, two pieces appear to be missing to be able to move forward on agency information technology goals: a near-term, publicized agency vision statement (i.e., an *all-encompassing* agency goal) and an accompanying information technology management-and-use strategy.

Figure 1 depicts a model information-technology management framework. At the forefront of this model is the agency *vision* statement followed by six statements of *direction* which support the agency vision. The selected vision should identify: the agency's objective and a timeframe by which the objective will be achieved. This is analogous to the process of constructing a new building. In this example, the end product is *envisioned* and declared (made public) through a blue-print, with a timeframe established as to when the building will be completed and ready for occupancy by its tenants. In this manner, all those involved in the operational (construction) process and those waiting to reap the benefits (occupancy) from the project clearly understand their roles and expectations.

Recommendation: Establish Forums to Introduce and Review Information Technology-Related Issues and Projects

Integral to this working model is the encouragement of the creative, debating, problem-solving, and planning skills of individuals within the agency.

The Information Technology Oversight Committee should be activated with an initial and general charter to: review any and all agency activities, as appropriate, for their potential relationship to, and impact on, the management and use of information technologies within the agency, statewide. The

committee should be composed of selected agency programmatic and administrative managers and regional office-based case managers. The committee should meet regularly and should establish and enforce rules of order and information technology policies—as appropriate for the agency, as a whole.

Current users of computers vary in their skill levels. As new technologies are introduced into the agency, users need a forum to discuss similar technology related-problems, thereby learning from the experienced. The Users Group should be established as the forum for both problem-sharing and idea-presenting. In support of this group, a computer bulletin-board system could be established to serve as the central repository of historical computer-related user problems. Users, through devices called modems, could have on-line access to the board and could scan it for *known* problems and their resolutions.

Recommendation: Position Staff to Optimally Use Information Technologies Toward the Realization of the Agency's Vision and Goals

This recommendation suggests certain activities be developed and implemented within the agency to help ensure that users in the agency's offices: (a) will know how to use new technologies as they are installed; (b) will be receptive to the new technologies proposed for them; and (c) will be technically supported in the use of new technologies.

Recommendation: Maximize the Agency's Return on Its Information Technology Investments through the Simultaneous Implementation of Multiple Networking Solutions

It is recommended the Continuum of Care proceed slowly in its intentions to implement sophisticated computer-based technologies to its staff statewide. This position is reinforced due to (a) the numbers of users within the agency currently not prepared to make optimal use of new, powerful computers, and (b) an immediate need among Regional Offices for a capability to easily and quickly communicate with other agency offices, other state agencies, and external organizations.

POTENTIAL BENEFITS THROUGH IMPLEMENTATION OF THE STUDY RECOMMENDATIONS

Potential Benefits from a Management Perspective

- Improvements in the *management oversight* of agency information technology and related projects
- Improvements in *quality management* of the agency's information resources
- An enabling of *responsibility-sharing* of client information among State and Regional Offices
- Increases in the likelihood of *cost-effective and successful* projects through proper project planning
- Enhancements to the *agency's image* in the areas of planning and accountability

Potential Benefits from Case Manager and Staff Perspectives

- Provides the *opportunities for administrative relief* to case managers
- Provides *multiple, short-term networking solutions* for easier and quicker access to information statewide
- Enables *users* within the agency the opportunity *to impact future information technology planning and purchasing decisions*
- Positions agency staff to *increase their abilities to respond* to internal and external inquiries through their use of new information technologies

Figure 1

THE VISION OF THE CONTINUUM

HAVE AN AGENCY INFRASTRUCTURE CAPABLE OF SERVING 600 SED CHILDREN BY 1996

STATEMENTS OF DIRECTION

1.	IMPROVE THE QUALITY AND ACCESSIBILITY OF INFORMATION
2.	GIVE OWNERSHIP OF CLIENT INFORMATION TO REGIONAL OFFICES, AS APPROPRIATE
3.	ENHANCE INTRA-AGENCY COMMUNICATIONS
4.	EMPHASIZE THE RESEARCH PROCESS AND TOOLS TO ENABLE IMPROVED ANALYSIS OF CLIENT DATA
5.	MINIMIZE CASE MANAGER ADMINISTRATIVE TASKS
6.	ENHANCE AND PROMOTE AGENCY'S IMAGE

AGENCY STRATEGIC INFORMATION RESOURCES PLAN

TELECOMMUNICATIONS STRATEGIC PLAN	INFORMATION SERVICES STRATEGIC PLAN	MICRO/REPRO-GRAPHICS STRATEGIC PLAN

ACTION PLANS

APPLICATIONS	QA	TRAINING	SUPPORT	COMMUNI-CATIONS	EQUIPMENT	SECURITY	DISASTER RECOVERY

VISION:	INTERDEPENDENCIES:
GOAL:	CONTINGENCY PLANS:
ENABLING STRATEGIES:	TIMEFRAMES:
OBSTACLES:	PRIORITIES:

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Figure III.C.1 I.T.Use-and-Management Framework

COMPUTER TRAINING FOR THE HEALTH CARE PROFESSIONAL

Presented by:

Alan M. Kaplan, M.S.W.
Director of Information Systems

Steven Kregness, B.S.
Senior Programmer/Analyst

Nancy Lorch
Database Coordinator
San Diego-Imperial Counties Developmental Services, Inc.
San Diego, CA

This paper will discuss training health care professionals to incorporate the use of computer technology into their jobs. Persons in the health care and social service fields are often not the most receptive persons to train in the use of computer technology. The reason as to why a person, particularly from these fields may not be receptive to this technology will not be discussed in the paper. What will be presented are some factors which an organization should consider to foster the incorporation of computer technology in the most effective manner process possible. For a rather interesting discourse on why persons from these fields might react as they do to new technology, the reader is referred to the book by Robert Pirsig, Zen and the Art of Motorcycle Maintenance[1].

The paper will discuss the concept of training as it applies to this task, what the organization must do to foster the training process, specific ways and examples of how to adapt training methodology and materials for this purpose, and finally a review of the use of software to assist with this purpose.

The issue and definition of what constitutes training has been the inspiration of several books, and a formal definition consumes a quarter of a page in Webster's Unabridged Dictionary. For the purpose of this paper, we are referring to training as the device used by an organization to promote the perceived benefits of computer technology into the job performance of its employees. In her workshop manual You Can Teach Others[2], Ida Rush George states "Training improves one's job performance in the present job, in a job one has just been selected to perform and in a job one is being promoted to perform." Sue Vineyard provides an even more operational definition, and one which

would fit with the premise of this paper, in her book The Great Trainer's Guide."[3] She states, "... training is, whatever it is needed to be to accomplish immediate success and/or life-long satisfaction."

How successful an organization is in having its staff incorporate the use of computer technology is directly dependent on the commitment of the administration. "Even excellent training will make little or no difference if it is not followed up, i.e., if its behavioral effects are not carefully reinforced by in-place systems."[4]

When organizations adapt or expand the use of computer technology, the change in the way business is conducted usually affects a majority of its employees. Organizations need to develop training opportunities to prepare their employees for the change. The actual, or anticipated change requires training. Change in an organization is implemented through training. As stated by Elaine Yarbrough, PhD and Paul Friedman, PhD, in their book Training Strategies from Start to Finish[5], "Training creates a bridge from the status quo to the desired state of affairs by providing appropriate learning experiences."

Everyone seems to react differently to change. A change in the operations of an organization, and especially in the way an employee conducts their job, can be extremely traumatic. The manner in which an organization assists its employees to accommodate this change is directly reflected in how the training is provided. Some concepts related to how adults learn may help explain why some training applications may actually increase employee stress, instead of providing the necessary skills to cope with the new situation.

Ron and Susan Zemke in their paper "30 Things We Know for Sure About Adult Learning[6]" discuss why a training opportunity may provoke rather than alleviate stress. One reason they describe is that "Adults have something real to lose in a classroom situation. Self-esteem and ego are on the line when they are asked to risk trying a new behavior in front of peers and cohorts." They also discuss that even in a non-classroom training situation, adults tend to let errors affect their self-esteem. They tend to apply tried-and-true solutions and take fewer risks.

What might an organization do to increase its chances of success in training its staff and incorporating the use of computer technology? Support by the administration and proper planning are essential for success. As the Zemkes describe, "Integration of new knowledge and skill requires transition time and focused effort."[7] This means that the training process must be integrated into the daily routine with the overall plans encompassing accountability and follow-up training. Also crucial to this process is the involvement of the immediate supervisor, both in the pre-course planning and any follow-up activities. "Training can improve performance only if the environment is supportive of that change."[8]

To help staff become more at ease on the computer, the training strategy should allow ample time for staff to learn and become comfortable with their new assignment. This may involve reducing work loads during the initial learning period. Practice time must be provided in order for staff to apply their new knowledge. It is very important that practice take place as soon as possible

while the training material is still fresh in their minds.

Another factor that can be critical in determining how well a person performs in a new situation is motivation. As mentioned earlier, most adult learning situations involve change of job or work assignments. These are reasons why a person must learn the new skills being taught. If it can be demonstrated that there are other personal benefits, the trainee will be more involved and less resistive. They will pick up the new skills faster and retain the information better.

When establishing a training regimen for staff, be prepared to spend sufficient time in planning and preparation. If possible, training sessions conducted in small groups are quite effective.

In developing a training strategy, it is always best to start slow and cover the basics. Never assume that the trainee knows something that is critical to the application. Whenever possible, trainees should be grouped based on level of expertise. If the group consists of users with varying degrees of experience, it will be difficult to plan the session.

Another effective way to group trainees is by type of tasks to be performed. For example, support staff may typically perform data entry while administrative personnel may focus more on running reports. It is very helpful to know the type of job the trainee will be performing.

As an example of developing separate training strategies at our agency, the San Diego Regional Center, training is conducted in two major areas. Staff are trained to use the San Diego Information System (SANDIS) and word

processing software. These two applications are quite different, and training strategies are just as different.

All staff at the agency have a need to use SANDIS, but for a variety of tasks. Everyone from the switchboard operator to the Executive Director has a need to know how to look up consumer information in the data base. Case management personnel need to know how to update consumer information, as well as how to use it. For example, the SANDIS system provides an Automated Annual Review for consumers. Therefore, case managers must know how to produce the Annual Review, and how to update the information.

Staff turnover occurs and it is critical that a new staff person be trained on the system as soon as possible. Staff do not have the luxury of letting their workload fall behind because they are new. In order to assure that staff learn these required skills, training sessions are provided on a regular schedule. It is the supervisor's responsibility to see that the new staff person enroll in class as soon as they are hired.

SANDIS training is divided into four major areas: updating consumer/ resource files; using the Match Program to locate resource providers for consumer needs; generating consumer requests (for transportation services; referrals for evaluations; and purchase of service); and Inquiry, or how to locate information, generate lists, and run reports.

When developing a training schedule, keep in mind that "burn out" will occur if training sessions are too long. With that in mind, the SANDIS training program is conducted in two-hour training sessions, each covering a different

topic. If given a choice, try to arrange morning sessions, but not too early. Give staff enough time to get to work, deal with any "emergencies" and have a cup of coffee. Keep in mind, however, as the session approaches the lunch hour, the trainee's thoughts will wander to food, and this is to be expected.

Try to arrange small groups for computer training sessions. This allows the trainer to be more attentive to each trainee. Trainees tend to feel more comfortable asking questions if they are in smaller groups. Also, hands-on training will provide a better understanding of how to use the program, and the new knowledge will be retained longer.

Hand-outs can be an effective way of relaying critical information. As a trainer, you may find that as you are trying to make an important point, all the trainee's heads are down as they write notes, and no one is watching what you are doing. If possible, develop handouts for essential information. For example, a SANDIS function key summary has been prepared outlining the use of these keys. This is critical information, and it is reassuring to the trainee that they will have something to reference when they are back at their office.

It is beneficial to refer to manuals or documentation in the course of the session. By relating the training topic to a specific chapter, the trainee also learns how to use the documentation for future reference.

Assist the trainee on the keyboard as much as possible. If there is a keyboard template, be sure to use it. For SANDIS training, labels have been placed on the keyboards to indicate the function of different keys. Throughout the training sessions, try to encourage "recall." After having repeated the

function key for a particular operation a few times, try pausing for a few seconds the next time to see if the staff person can recall the key.

Case management staff are required to attend four training sessions. By the third or fourth session, trainees are usually feeling much more confident (even those who said "I'll never be able to use a computer") and are beginning to understand how the whole system works. After the last session, the trainees are told that they have graduated and a Certificate of Completion is awarded.

Training personnel on word processing is much different and usually takes more time. The concept of word processing can be difficult to grasp if one is accustomed to using a typewriter. Sometimes the biggest hurdle can be trying to explain 'word wrap.'

It takes a lot of time and effort to train staff on word processing, especially in a large organization with numerous support staff. It may be useful to employ some basic training packages to assist with this process. Interactive diskette training programs are available for many software packages. Typing tutorial programs are also available to brush up on typing skills or improve speed.

Tutorial programs, however, will only take the trainee so far. When using the tutorials, the trainee is usually not "allowed" to make mistakes. This can lead to apprehension when it comes to performing the actual task. To bridge this gap, a training packet can be useful with self-guided exercises to be completed using the word processing program. As an example, a training packet was developed for use at our agency which consists of three exercises. The first exercise involves typing a simple letter, and uses text to prompt the trainee to perform the

correct step. The initial exercise takes the trainee through the basic steps: typing the letter, performing spell check, and printing the document. The second exercise involves making pre-determined revisions to the same letter, and repeats the steps of spell check and printing. The final exercise takes the trainee through the steps of using a "shell" or template to create a document.

After completing the training packet, the trainee still has one transition to make: typing "real work." To assist the trainee in this transition, it is useful to elicit the help of other staff in the trainee's department. A "Train the Trainer" session is periodically conducted for one or two staff members from each department on how to train new support staff on the basics of the word processing program. The "new" role as a trainer, the tutorial programs, and the training packet are discussed in this session.

This training process was modified to train case managers to use the word processing program. Small classes are used which meet a total of four times for 3-hour sessions. The first class covers the very basics: care and feeding of the computer and how to use the tutorial programs. The following three classes covers the exercises mentioned above in a classroom setting.

Almost as important as the initial training is on-going support. The trainee must feel comfortable using the program. If left to struggle, the trainee will feel frustrated. The more frustrated, the less comfortable they feel with the program, and the less likely they are to use it. Therefore, it is critical that the trainee have a place to go with questions.

Documentation or reference materials are also very important. When our

agency began using word processing software, we were faced with a dilemma: The manuals which came with the software were too complicated for most people to understand. It was decided that a user friendly manual would be created in-house to assist staff. The manual was developed using a desk top publishing program. This program has the capability of creating a table of contents and an index, both of which are crucial in creating a good manual. "A useful index is always a well-planned, handcrafted piece of work. "[9]

In addition to the need to develop custom documentation in-house, it may also be advantageous to develop customized on-line tutorials. There are a number of ways to develop tutorial packages with more coming out every day.

If one is a programmer, an interactive tutorial can be developed. Howerver, an experienced computer user without programming skills can create a demonstration package to familiarize the trainee with the screens and function keys.

The latest innovation in this field is the use of "Multi-media" software packages. This provides the opportunity to incorporate multiple sources (graphics, sound, text, and video) to present information. This is still in the beginning stages so prices for the hardware necessary to run "Multi-media" is still prohibitive to small budget projects. To use "Multi-media" one would need a computer with a good graphics adapter, a sound board, a mouse, a CD-ROM drive and "Multi-media" system software.

Another type of software are the "Presentation" packages. These are typically designed more for use in preparing charts/overheads/slides for business

presentations than for tutorial packages. They tend to lack screen handling and time controls to create on-screen presentations.

The third type has been, for the most part, ignored in the business world. This is "Slide Show" software. There are a small number of software packages that cover this area. These programs have several screen control features but may be difficult to use. Some of these will be upgraded to "Multi-media" capability during the next few years.

A good software package must have strong screen handling capabilities with screen fades, scrolls, and timing controls that allow one to vary the timing of the screens in the tutorial. It should also have screen capture capability to incorporate screens from the software into the tutorial. A package that contains some programming capabilities will allow the user to control which sections of the tutorial is viewed. Finally there should be a separate (runtime version) slide show program. This will allow the production of multiple copies of the tutorial.

Selecting the package is only the beginning. One must be knowledgeable of the software for which the tutorial is intended and know how it will be used by the intended audience.

The next step would be to create an outline. For example, when teaching data entry, maybe a short paragraph on how the data entry fits into the overall system might help. Demonstrate how the work in one area can help reduce work in another area.

The outline can be used as a script. Include what screens are necessary to demonstrate the software, and what additional information is needed to

explain what is seen on the screen. Next load the screen capture software and copy the screens needed in the tutorial. As the screens are being copied, ask what questions would a new user have at this point. Those questions would make a good follow-up information screen. Be sure to write down the file name of each screen as they are saved in the screen capturing program.

One may be a little creative in the next step in the process. Create overlay boxes and instruction pages that explain information on the screen, or about the chapter or section that follows. Enter the script into the program using the file names from the captured screens. Test the timing of the screen changes, and decide if they should be automatic or controlled by the trainee.

When satisfied with how it runs, let someone test it out who has not been involved with the development. Have them list strong points and where further clarification may be needed. What might be obvious to someone familiar with the software may not be obvious for a new user. Incorporate suggestions and make changes as needed. One now has a tutorial based on the organization's unique style of business or its information system.

In summation, a well planned and executed training strategy is crucial for the successful incorporation of computer technology into the delivery system of a health care agency. This strategy needs to insure an administrative and work environment supportive of this change, as well as adapted training approaches and materials suited to the unique needs of the organization.

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THE SOUTH CAROLINA COMMISSION ON AGING: AN AUTOMATED STATEWIDE SYSTEM OF CASE MANAGEMENT FOR THE ELDERLY OF SOUTH CAROLINA

Presented by:

Matthew Lynch, B.S.
Management Information Systems Director

Peyton Woolridge, M.S.W.
Long Term Care Program Consultant

Jeanette Bodie, M.P.H.
Research Planner
South Carolina Commission on Aging
Columbia, SC

The South Carolina Commission on Aging Client Information System: An Automated Statewide System of Care Management for The Elderly of South Carolina

Presenters:
Matthew E. Lynch, Management Information Systems Director
Peyton Wooldridge, Program Consultant
Jeanette Bodie, Planner

BACKGROUND

By 1984 it became more apparent that the South Carolina Commission on Aging (SCCOA) needed to find ways of incorporating automated procedures into its operations. Until that time office automation was limited to the agency accounting system, which operated on a mainframe computer housed at the University of South Carolina. A Management Information Systems (MIS) Committee, established on August 1, 1984, was given the responsibility of identifing the basis under which approval could be obtained for funds controlled by SCCOA to participate in the acquisition of Data Processing Software and Hardware. The Committee originally consisted of representatives from all areas of the Aging Network three Area on Aging Agencies, three Local Service Provider Agencies and three State Agency staff.

On April 2, 1985, After securing input from the aging network, the Committee adopted recommended guidelines regarding Automated Data Processing (ADP) equipment and software. With the approval of the SCCOA Commissioners, these guidelines became a part of the SCCOA Manual

of Policies and Procedures under the Older Americans Act on May 3, 1985.

The Committee also recommended that the SCCOA develop a Model Management Information System. Recommendations for a Local Service Provider to serve as a pilot test site were solicited from Area Agencies on Aging. Lancaster County Council on Aging (LCCOA) was selected from the responses.

HEALTH IMPAIRED ELDERLY PROJECT

Considerable time and effort was spent in aquiring and reviewing client tracking systems, case management systems, and data base management systems from both private and public sources nationwide. It was determined that the Health Impaired Elderly Project was the only system both sophisticated and comphrehen-sive enough to satisfy the needs and expectations of the Committee. The Health Impaired Elderly Project (HIEP) funded from the Robert Wood Johnson Foundation of Princeton, New Jersey, was administered by Community Care Inc. of South Carolina under contract with Central Midlands Regional Planning Council (CMRPC) from February 1980 through February 1984, after which the CMRPC assumed direct administration for the project.

Operating from a central location at CMRPC the project provided for the storage and analysis of data collected on elderly clients from the four county Central Midlands Region consisting of Lexington, Richland, Fairfield , and Newberry Counties. The main goal of the

project was to demonstrate that public and voluntary agencies (working together) could develop a system to link health and social services together for the benefit of the health impaired elderly. Of significance to the implementation of a computerized client information/client tracking system was the projects development of a comprehensive client assessment form which incorporated the Administration on Aging (AOA) and State Agency on Aging report requirement guidelines.

Adapting the HIEP system was a problem since the SCCOA had neither the staff nor the resources to implement and support a centralized statewide database system of data collection for support of elderly services. The Committee felt that a "management information system" should reside within the boundaries of the local service provider. After numerous meetings and considerable input from the MIS Committee, Area Agencies on Aging and SCCOA staff, it was decided that the SCCOA Client Information System (CIS) should be developed within the micro computer environment and be based on the data elements contained in the HIEP System. In order to accomplish this, SCCOA contracted with the University of South Carolina, Network Services Division, to assist with the design of the SCCOA CIS and to provide all programming and system support.

SCCOA CIS

Pilot site testing of the SCCOA CIS began in 1986 in five counties. Since that time Installation of the system has grown from

thirteen Local Service Providers in July of 1988 to forty-two users. Full utilization by all remaining Service Providers is expected by July 1992. In keeping with the original objectives of the MIS Committee, The South Carolina Commission on Aging Client Information System (SCCOA CIS) was designed to be utilized as a stand-alone system in support of a single provider agency. It provided an easy-to-use system for recording and tracking client assessments and use of services. SCCOA CIS will also operate on a Local Area Network and as a part of a centralized system linking service providers, area agencies and state agencies.

Written in **dBase III Plus** and compiled in **Clipper,** SCCOA CIS operates on an IBM or compatible 286 micro computer with a minimum of 640K of memory and a 40MB hard drive. Dbase is a relational database management system and an industry recognized standard for micro computer database development. Utilization of this third generation programming language gives SCCOA CIS the flexibility of being used as is, or allowing users to develop in-house specific management reports on their own.

Recognizing the need for continual improvement, the original system has gone through numerous revisions and enhancements. The current SCCOA CIS provides an accurate, professional and standardized means of assessing the risk factors, care-support structures, functional abilities and medical and mental health status of the elderly. In addition, it provides a complete history of each client's assessments while tracking the on-going status or changes in each

client assessment.

The system allows agencies to better track and administer current service delivery resources as well as plan for future service needs. It facilitates the recording and tracking of a range of services from a variety of both public and private providers as well as varied funding sources. Completed assessment information serves as a basis on which to carry out a care management plan and assign services to the client.

SCCOA CIS also allows easy tracking of client service use, detailed client demographic, and indepth client assessment. User-friendly screens have been incorporated into a menu-driven system which simplifies data entry and report generation. Preprogrammed System reports are designed to meet federal Title III program and SCCOA reporting requirements.

Comprehensive support to all SCCOA CIS users is provided, under a yearly maintenance contract, by The University of South Carolina. User support includes extensive on-site or university training, detailed user materials, telephone support, and an active users group.

CATALYSTS FOR CHANGE

The South Carolina Commission on Aging recognized early on that the SCCOA CIS would be an ever changing instrument; but, who would have input into reshaping the system? If the SCCOA CIS was to fulfill its task of supporting the agency mission of improving the life style of

older adults, than it was clear that all possible areas of influence most remain open. This unique concept highlights the Commission on Agings' recognition that it exists to serve the client, not itself.

Mechanisms for change to the SCCOA CIS are influenced from a multitude of sources. The SCCOA CIS Users Group is provided with a yearly budget to support any modifications and enhancements which the group agrees upon. As the end user of the system they are the true owners. Their influenced is best seen in the systems ease of data entry and data manipulation. SCCOA staff input is influenced by internal agency concerns as well as state and federal reporting requirements. A sister program to the SCCOA CIS is the Client Summary System (CSUM), which produces all federal reports. Other state agencies provide funding for certain services, and their report requirements are built into the SCCOA CIS. Modification of the system is also influenced by both new data and methods of service.

THE SOUTH CAROLINA PANEL STUDY OF OLDER ADULTS

In the middle 1980's an ad hoc group of State agency staff and policy-makers began to discuss the lack of data on the characteristics and needs of South Carolina's older population. Agency planners were often called upon to make projections about current and future needs for health and human services or to analyze the potential impact of various State and Federal proposals for changes in the financing and delivery of those services. Since there was no comprehensive base of South Carolina specific data on our older population, planners were

forced to apply assumptions from national studies to South Carolina population data from the U.S. Census in order to make rough estimates.

South Carolina is not typical of most states, thus making the use of national averages in making projections about South Carolina a less than ideal approach. South Carolina shares certain characteristics with other Southern states, such as high poverty, high minority population, low educational status; however, it is also experiencing a population explosion in the coastal areas, which includes the in-migration of relatively affluent retirees.

After several years of meetings and discussions of various ways of addressing this information deficit, consensus was reached among the member agencies of the Long Term Care Council that a comprehensive statewide study of the older population in South Carolina should be conducted under the auspices of the Council. It was also agreed that the study should be designed so that longitudinal data could be collected in the future to study changes in the original study participants over time. Thus the South Carolina Panel Study of Older Adults was born.

Six state agencies contributed funding to the Panel Study and participated in the design of the study. Those agencies were the State Health and Human Services Finance Commission, the Commission on Aging, the Department of Health and Environmental Control, the Department of Social Services, the Department of Mental Health, and the Department of Mental Retardation. Contractors for components of the study were the

Institute of Public Affairs at the University of South Carolina and the Division of Research and Statistical Services of the State Budget and Control Board. The Heartland Center on Aging, Disability and Long Term Care at Indiana University, one of ten National Long Term Care Resource Centers funded by the U.S. Administration on Aging, provided technical assistance and consultation on the design of the study through its relationship with the S.C. Commission on Aging.

In addition to the Panel Study, a regional analysis and report has been written by Heartland Center on Aging for each of the ten Area Agencies on Aging. A follow-up survey of informal caregivers has been completed for the Commission on Aging by the Institute of Public Affairs at USC under a Federal grant from the Administration on Aging. The data is being analyzed at the Heartland Center on Aging.

One outstanding finding of the Panel Study is what a major role education plays in determining our future. A look at the educational attainment of our older population also tells us something about our past. It is somewhat discouraging to discover that almost 40 percent of our population age 55 and over has less than a high school education. It is even more distressing to discover that over 60 percent of our population age 85 and over has less than a high school education. However, it is important to place this phenomenon into its historical context.

Lack of a high school education is twice as high among the minority population. Prior to the 1930's less than one in five

minority individuals completed high school, while more than half of the non-minority population completed high school.

Why is education important in a study of the older population? Education is important in the context of this study because it is a powerful predictor of one's health status and quality of life. For example, those in our survey with less than a high school education were twice as likely to rate their health as poor when compared to those with a high school education or higher. Those with less than a high school education are almost three times as likely to have difficulties with three or more activities of daily living, and they are three times as likely to live at or below the poverty level. The choices we make or that are made for us regarding our education will have a powerful impact on us throughout our lifetime.

For many of those who participated in the study, it may be too late to undo the effects of their educational choices, but that is not to say that all is hopeless. Interestingly, almost half of those who participated in the study reported having made a change in their lifestyle to improve their health in the last two years, such as exercise or diet changes. This indicates that a significant number of older people believe that it is possible to improve one's health by prevention efforts. This is important to the Commission on Aging, because it is the premise on which our senior citizen's center development program is based. We have argued that health promotion and prevention programs offered through senior centers can help to improve the health and well-being of our older population. This data at least

verifies that many older people believe in these types of activities as well.

An important point to remember in considering the findings of the study is that the vast majority of our older people are in relatively good health and function independently. This is fortunate, because the relatively small number who are not in good health may be in need of expensive medical or long term care services. Unfortunately, the people in the worst condition and in need of the most services are those on Medicaid, for whom we all have to pay. For example, people on Medicaid were seven times as likely to report difficulties with activities of daily living than those above the poverty level.

This fact is particularly disturbing in the context of the long term care system. South Carolina currently spends almost $200 million on nursing home care under the Medicaid program. The total number of nursing home residents in South Carolina is approximately 18,000 according to the 1990 Census, and somewhere between 80 and 90 percent of them are Medicaid eligible.

Based on our study results, it is estimate that there are 18,000 people living in the community with limitations in three or more activities of daily living such as feeding oneself, bathing, dressing or going to the bathroom, and 60 percent or about 11,000 are potentially Medicaid eligible for nursing home care. Although these people are currently in the community, their level of disability indicates that they are likely candidates for nursing home placement in the not too distant future. One doesn't have to be an expert to

appreciate the potential financial impact on the state if all of these people were to suddenly demand nursing home placement.

CARE MANAGEMENT FOR THE ELDERLY OF SOUTH CAROLINA

> "Care management is a set of activities designed to enhance accessibility of services, to match services to each individual's needs. to co-ordinate delivery of services and to ensure the quality of service".
>
> State Perspectives on Long-Term Care Management Systems: Implications for Federal Policy
> American Association of Retired Persons, Public Policy Institute, 1991

The essential activities which constitute care management include: screening for potential care management services ;comprehensive client/support system assessment(s); comprehensive service planning; negotiation(s) for service(s);monitoring service(s) delivery; re-assessing client/support system needs; extensive documentation; termination of care management services when appropriate.

Care management is not a "new" service. What is emerging as new or perhaps changing are three essential issues: (1) the definition of exactly who is performing the care management activities (2) also emerging is the "targeting" of certain categories of clients/support systems who may be in highest risk/need for the care management

services.(3) the nature and degree of date collection and documentation that is essential to support care management service delivery.

Who are the care management clients? A typical profile might be a woman in her eighties needing moderate to heavy regular assistance with two or more ADL, and with some mild to moderate cognitive impairment. Because of her confusion, she can not be left alone safely, and her children all work during the day.

Another client might be a younger old person male in his mid to late 60's being discharged from a hospital or rehabilitation center following a major stroke who has family in the immediate vicinity but the family has been exploiting the elder and wants their social security check and is not interested willing or motivated to perform the caregiving responsibilities or oversee the care being provided from others.

Another type of potential care management client can be found in the affluent well- elderly who retire to resort and retirement communities and "age-in-place" and have no family nearby to help in times of crisis .In addition, often these community aging services are already strained to the maximum and cannot accommodate the vast numbers of frail elderly.

With this modern blended family lifestyle, children and grandchildren often do not live with their aging parents as was the trend in the olden days. More often that not the older person lives alone, and

prefers that- until there is a health crisis, necessitating a relocation to either the children or to a long term care facility.

Also, in today's highly mobile society, aging parents and children can live cross continents from one another. This raises the issue of long distance caregiving and the role of the community in supporting older persons who are alone. One on the emerging trends is a higher level of responsiveness of corporation with family caregiving benefits for dependent care.

In 1989 a survey conducted by staff of the University of Minnesota Long Term Care Resource Center revealed that the practice of "case" management varied greatly from provider to provider within the aging network. There was little consensus as to what the service was, how it was to be performed and what documentation was needed to account for the service being offered.

In terms of care management and the network - Many "hybrid" activities associated with that service delivery case were identified, and the unit costs varied from $.22 per staff hour in a county that cost allocated case management as general administrative overhead with no designated staff or activities to over $19 in a county with trained MSW practicing a high level of "true" comprehensive managed care as a distinct service.

As a result of that in-depth survey, a Information and Referral and Care Management Task Force was formed in the early Spring of 1990 to

address some of the unresolved questions proposed by the study:

Who are the care managers?

Historically, individual clients needing medical, supportive or functional care were perceived as the original "managers" of their own care, making decisions and taking action to get their needs met. In situations where the individual client was too ill or otherwise incapacitated to decide about their care, often the family or significant support network functioned as the "informal" care managers and decision makers on behalf of the client.

Changing trends in contemporary health care and family life have witnessed the emergence of the paid or "formal" care manager. This is becoming more prevalent particularly: (1) when the client is frail, alone and unable/unwilling to make decisions and negotiate for needed services;(2) where there is no family, or no reliable surrogate decision-making person in the client's support system , either willing to make decisions or recognized as having the authority to do so.

These paid/formal "care managers" can be found in a variety of settings: physicians in their private offices, long term care insurance counselors, home health nurses and social workers, hospital discharge planners and a conglomeration of independent professionals who have self-designated themselves as private geriatric care managers practicing either in affiliation with a single agency or cluster of agencies or in solo private practice.

In a litigation-sensitive society, the responsibilities and activities of these surrogate decision makers are falling under increasing legal and ethical scrutiny. And the significance of well-documented client information cannot be underestimated.

What kind of data system is necessary for case management in the aging network?

The Minnesota study pointed to the need to consider the many uses of data - by whom, for what purposes- to help providers track client needs over time and adjust service plans: to generate regional and statewide data to assist in broad sweeping planning and policy and advocacy functions, and to allocate resources to on the regional and local levels.

Problem areas identified:

(1) inconsistant intake and client screening techniques
(2) lack of a uniform client assessment statewide, and corresponding variances in how and how completely these were completed
(3) lack of comprehensive service planning
(4) Inconsistant case and services monitoring documentation
(5) Discrepancies between the various agencies regarding their automated data collection capacity

The Care Management task force as part of an overarching quality assurance initiative of the SCCOA has developed a care management

philosophy, standards and indicators which were approved December 1990 by SCCOS commissioners. Since that time the task force has drafted a draft uniform client assessment and various versions of client screening and prioritization forms to utilize.

These and other components of the service monitoring system will be tested in pilot sites in the Fall 1992 . Depending on the outcomes , some or all or modified versions may be proposed for statewide adoption and implementation by July 1993.

Areas needing attention:

1. integrating our intake, client screen , client prioritization and assessment into a uniform, smoothly flowing data process that builds on each component;
2. Having more distinct and measurable client "outcome" standards. As care management grows as a separate service, this will become more obvious;
3. Linking our system with other human service state systems so that clients access service quickly without unnecessary duplication or unfortunate gaps in service from the point of first inquiry to actual service start-up.
4. Have a more consistent guideline regarding documentation and upgrading of client information and changes in service delivery when indicated. Currently this ranges from one worker writing "home visit made today" in one agency, while in an adjoining county, a full page of narrative is written to describe details of a parallel home visit.

5. guidelines about "best practice" activities and issues of risk management and tort liability for care management as a separate service.

CONCLUSION

To achieve the goal of assisting older adults to remain integral members of the community SCCOA will continue to support and develop a comprehensive system for data collection, analyst, and research. Computerized client systems can not be viewed as end products unto themselves. They are ever changing tools which need to be utilized to improve operations, provide improved client services, to enhance legislative positions, and assist in funding.

AN INNOVATIVE APPROACH FOR THE SELECTION OF CHILDREN WITH SEVERE EMOTIONAL DISTURBANCES

Presented by:

Wendell Price, M.S.
Director of External Relations

Melanie D. Burnett, B.A.
Selection Process Administrator

Kerry T. Hinkle, Ph.D.
Psychologist
South Carolina Continuum of Care for Emotionally Disturbed Children
Columbia, SC

SOUTH CAROLINA CONTINUUM OF CARE

AN INNOVATIVE APPROACH FOR THE SELECTION OF CHILDREN WITH SEVERE EMOTIONAL DISTURBANCES

The Continuum of Care was created by the General Assembly in 1983 to meet the service needs of severely emotionally disturbed children who require an organized and comprehensive system of care. The severity of the behavior displayed by these children necessitates the coordinated efforts of multiple service agencies (e.g., Mental Health, Education, Social Services, Juvenile Justice, Mental Retardation, etc.). In addition, the traditional service delivery system has proven unable or unsuccessful in providing the array of services needed to intervene on behalf of such youth. In an effort to supplement existing services, the Continuum provides interagency case management, procurement of private as well as public services, and client advocacy for its clients who have been identified as severely emotionally disturbed.

Minimum eligibility criteria must be met before a child can be considered by the Continuum. The child must:

***be a legal resident of South Carolina;**

***have not yet reached his/her eighteenth (18) birthday, or be enrolled in a Special Education program for handicapped pupils;**

***be certified as severely emotionally disturbed by a psychiatrist or licensed clinical psychologist or a SC Department of Education Certified School Psychologist;**

***have emotional disturbance which has persisted for a least one year in spite of documented interventions provided in a therapeutic manner;**

***have treatment needs which are not being met by the existing service delivery systems and which require a comprehensive and organized system of care; and**

***consent to, or if a minor, have informed consent of parent(s) or legal guardian(s) for, services and treatment coordinated and delivered by the Continuum of Care; and consent to, or have informed consent for, release of information to/by the Continuum of Care.**

Severe Emotional Disturbance is the inclusive term for children and adolescents whose severity of emotional, mental or behavioral disturbance requires a comprehensive and organized system of care. As these parameters indicate, the designation of "severe emotional disturbance" among children reflects a two dimensional relationship between the severity of the dysfunction and the system of care necessary to meet the needs of severely emotionally disturbed children and adolescents. This two dimensional description can be further

defined as:

Severity of Dysfunction - In order for a child to be considered severely emotionally disturbed, the child's behavior must exhibit the following characteristics:

Frequency The behavior shall have occurred with sufficient frequency to be considered a pattern of situationally inappropriate behavior which deviates substantially from behavior appropriate to one's age and cultural peer group.

Intensity The behavior shall have occurred with sufficient intensity to be considered seriously detrimental to the growth, development or welfare, or the safety and welfare of others.

Duration The behavior shall have occurred over an extended period of time or to the extent the problem is disabling, handicapping or in some way interferes with the effective functioning of the individual.

System of Care - The severity of the problem shall indicate the system of care necessary based upon the following criteria:

Range of Service The severity of the behavior is judged to require a range of services which necessitates the involvement of multiple agencies.

Disruption The severity of the behavior is judged sufficiently disruptive to lead to the removal of the child from his or her current home, school, community or therapeutic setting.

Persistence The severity of behavior is judged persistent in spite of documented interventions provided in a coordinated and therapeutic manner.

Due to budgetary restraints on the number of slots available and since there are more applicants than available client slots, the selection of Continuum of Care clients involves both a priority ranking system as well as an independent selection panel. As mandated by Statute, the Continuum is charged with the responsibility of selecting from among the most severely disturbed children in the state. Consequently, a selection system which ranks applicants in terms of severity of dysfunction and system of care has evolved. This method combines qualitative information into a quantitative procedure for ordering applicants for review by an independent selection panel.

The Continuum of Care selection procedure was created to increase reliability, minimize subjectivity and ensure equity by neutralizing individual and system biases based on sex, race and gender, as well as, availability, accessibility and acceptability.

In order to operationalize this procedure, a weighted application was designed which collects information in a formal and objective nature regarding the various subareas of the Continuum of Care SED definition (frequency, intensity, duration, range of service, disruption, persistence). This data is entered into the Applicant Scoring System and an eligibility score is calculated and recorded by computer.

Applicants are then placed on a Waiting List based on their Priority Ranking. Priority ranked applicants compete for regional slots as openings become available. Clients are then selected by a selection panel of independent individuals who are not otherwise associated with the Continuum.

The Applicant Scoring System is designed to monitor the status of applicants, update information and scores, and transfer applicant data to the Client Information System (CIS).

ARE APPLICATIONS FOR A COMPUTER-BASED SYSTEM DESIGNED TO PROVIDE LINKAGES BETWEEN THE HEALTH SCIENCE CENTER AND REMOTE OR RURAL HEALTH CARE PROVIDERS AND HEALTH CARE RECIPIENTS?

Presented by:

Sherald A. Ramirez, B.A.
KARENET Director

Judith Flagle, Ed.D.
Assistant Professor, Occupational Therapy
Texas Technical University Health Sciences Center
Lubbock, TX

ARE THERE WORLD-WIDE APPLICATIONS FOR A COMPUTER-BASED SYSTEM DESIGNED TO PROVIDE LINKAGES BETWEEN A HEALTH SCIENCES CENTER AND REMOTE OR RURAL HEALTH CARE PROVIDERS AND HEALTH CARE RECIPIENTS?

By

Sherald A. Ramirez, B.A.

Director of KARENET

Texas Tech University Health Sciences Center

School of Nursing

Lubbock, TX 79430

U.S.A.

KARENET is a computer network that facilitates linkages between the Texas Tech University Health Sciences Center (TTUHSC) and remote and/or rural providers of health care and recipients of care. Features of the KARENET system include continuing education courses for health care providers, patient management protocols, patient education and information, and the KARENET Automated Health Care Record.

Continuing Education Courses

Health care providers living in rural or remote areas have difficulty traveling to educational centers to take required continuing education courses. In the 108 counties of West Texas, there are approximately 23,974 rural health care providers served by four campuses of the Texas Tech University Health Sciences Center. Because West Texas encompasses approximately 144,000 square miles, a rural health care professional must travel several miles to take continuing education courses.

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KARENET has helped to bridge the gap between health professional education sites and rural health care providers by offering continuing education courses on the computer. By using a computer with a modem, a rural health care professional can take required courses on the KARENET computer at the Texas Tech University Health Sciences Center. These courses are easy to access and use; someone with very little or no computer experience will have no problems taking the courses.

All courses offered by KARENET are written by Texas Tech University Health Sciences Center School of Nursing or School of Medicine faculty and are accredited through the respective schools. Once a professional successfully completes a course, a certificate of continuing education credits is sent to the student. The costs to take these courses are $50 for each CEU taken.

A typical course includes several screens of information followed by a short quiz of the information presented. For each question asked of the student, feedback is displayed for both incorrect and correct responses. To take the course the student only needs to press one key to move forward or backward through the screens of the course.

Courses available from KARENET include subjects such as diabetes management, depression, suicide crisis, gerontology, emergency nursing, cardiovascular care, and maternal child health.

All courses are reviewed periodically by the authors and modified as necessary.

Patient Management Protocols

Protocols for medical and nursing patient management are also available to rural or remote health care professionals through the KARENET computer network. These protocols outline the most current treatment modalities in many areas of patient management.

Written by experts at the Texas Tech University Health Sciences Center, these protocols facilitate consultation and referral from rural areas to a central health care site. The patient management protocols are also a way to disseminate timely information to rural and/or remote areas. In conjunction with the Regional AIDS Education and Training Center for Texas and Oklahoma, KARENET offers access to a Universal Precautions Protocol to all hospitals in Texas and Oklahoma. Any hospital with a computer and modem can view the protocol, free of charge.

Other Patient Management Protocols available from KARENET include protocols for trauma, burns, congestive heart failure, depression, DKA, pain, poison, respiratory distress, HHNK, cardiopulmonary resuscitation and treatment to name a few.

Patient Education and Information

In addition to patient management protocols, KARENET offers patient education courses and information. This patient information is designed to help health care professional educate their patients on illnesses and treatment of these illnesses.

The patient education courses available from KARENET are similar to computerized brochures and someone with no computer experience can easily use the computer to read the screens of information presented. By using this patient information tool, rural and/or remote health care professionals can inform their patients for very little cost.

Automated Health Care Record

The KARENET Automated Health Care Record automates the information necessary for comprehensive health care in hospitals, nursing homes, physicians' offices and clinics. The record is a tool that all health care professionals can use to document basic

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biographical and demographic information, as well as physicians orders and corresponding care documentation. The record also acts as a recording tool for lab requests and results. Progress notes and reports are also an important element of the record.

Because the record data can be easily transmitted by modem, the data can be used as the basis for conferencing about patient problems by personnel in sites remote from one another. In addition, a provider in one site can provide a level of supervision for personnel in a remote location by reviewing the records of patients.

World-Wide Applications

Throughout the world, health care professionals in rural and/or remote areas need linkages to a health science center or a similar entity for education, referral and consultation with other health care professionals.

The KARENET system has demonstrated how a computer network can link rural health care professionals to vital services and information of a health sciences center.

The KARENET computer network was developed after a thorough needs assessment was conducted for several rural health care sites in West Texas. From this analysis, it was determined that the greatest needs for professionals in rural and/or remote areas were access to education, consultation and referral. This same model could be transferred to other parts of the world to develop a computer networking system similar to the KARENET system.

INTEGRATING INFORMATION AND REFERRAL WITH CLIENT TRACKING SYSTEMS

Presented by:

Jacquelyn Vincson U'Deen, M.A.
Program Director
Children's Support Systems
LaRabida Children's Hospital & Research Center
Chicago, IL

Edward Hamlin, B.A.
Principal
Peter Martin & Associates
Chicago, IL

Integrating Information and Referral with Client Tracking Systems

Jacquelyn Vincson U'Deen, M.A.
Director, Children's Support Systems

Edward Hamlin
Principal, Peter Martin Associates, Inc.

Federal initiatives such as the Individuals with Disabilities Education Act (PL 99-457) are quickly changing the way human services will be defined, delivered, and tracked well into the next century. For the first time, the *family* has moved squarely into the foreground: hospitals, clinics, social service, case management, and community organizations are finding that it is no longer enough to target interventions solely at individual clients. Unfortunately, existing case management and service systems don't support a family-centered model of care. For the most part, they cannot provide the critical links needed to understand and serve a family's complex needs.

Children's Support Systems (CSS), a family-centered case management organization serving children with chronic illness, resolved to develop a computerized system that would address the needs of families, providers, and staff, all of whom are essential links in successful service delivery. In collaboration with the consulting firm of Peter Martin Associates (PMA), CSS has designed a comprehensive case management system now known as the **Family Care Tracking System**, or FACTS.

This paper examines the development of **FACTS** and a companion application, **Perfect Match,** a powerful Information and Referral (I&R) system. An overview of specific software capabilities will be presented, with an emphasis on the conceptual

framework of the system and the design challenges that had to be overcome in building a logical, user-friendly system. Organizational issues, such as the incorporation of staff ideas into the system's design, user training, and the move from a paper-driven system to a computerized system, will also be discussed. Finally, we will discuss various features slated for development in the near future as well as networking opportunities for better collaboration and coordination among providers.

Project Background

CSS Program Objectives Information management was a major objective of CSS when the program was begun in 1988. CSS is a community-based outreach program located in Chicago, Illinois, that links children and their family members with the existing network of services in their local communities. The program uses five paraprofessionals, called Family Advocates, under the direction of two clinical managers, a registered nurse and a social worker to coordinate services for families caring for children with chronic illness and developmental disabilities. The advocates, supplemented by the clinical managers, make weekly home visits to families and provide advocacy and problem-solving skills training, supportive listening and advice-giving while assisting caregivers in identifying and accessing services and generally acting as role models. CSS initially received private foundation support to develop the system and subsequently obtained state funding to meet design costs.

The Family-Centered Approach It was clear from the outset that any computerized system must be designed to address the child's medical and social needs *in tandem with* those of parents and other family members in the household who might need support. In keeping with PL99-457, it should implement a family-based model of service at all levels, including support for non-traditional family

structures. In practical terms, this meant the system should assist staff in managing linkages to a vast number of services as well as to those agencies already providing services to the family. From an organizational perspective, the system had to be user-friendly for individuals with no previous computer experience and must be viewed as helpful in the day-to-day work process. The system must also support internal program monitoring and evaluation, and activity reports required by funders.

Open Design Philosophy Early on, we took careful inventory of our case management documentation forms and our coordination protocol. These included forms for Intake, Family Needs Assessment, Individualized Family Service Plan (IFSP), Quarterly Progress Review, and Case Closing. From this review it was clear that the system must be maintainable, and to some degree customizable, by program staff rather than by the developers, especially from the perspectives of reporting, code and category definition, and client confidentiality. FACTS and Perfect Match were both founded on an open design approach which allows the agency to exercise a large degree of control over the way information is entered, stored and reported, enabling the systems to mirror the agency's own way of thinking about its services and its knowledge pool. Further, the software was designed from the outset to support multiple concurrent users, allowing for expansion within the agency as well as networking with other agencies. At CSS, all staffmembers have immediate access to FACTS via a seven-station local area network.

The Initial Prototype The initial design centered around building a general system for organizing client information. The Intake form, the first stage in our case management protocol, was targeted as the foundation of the system.

The first developer was a social policy analyst with a background in programming. Working with our project as a part-time evaluator and developer through the Chapin Hall Center for Children at the University of Chicago, he

developed a satisfactory intake procedure and system for organizing client information, using a software prototyping tool (Clarion). When we were ready to proceed with further development, we discussed our plans with the programmer and it was apparent that our system's needs were beyond his capabilities. At that point we decided to solicit additional expertise.

At first, we hoped to hire an individual who had both a social science background and programming skills. We found, after many months of interviewing, that individuals with skills in both social work and computer programming were in short supply. Having become somewhat more literate in the computer environment, we determined it was not necessary to have a person with a social or medical background. Rather, the critical factor was an individual who understood systems. Thus we went to the private sector for a developer.

We were fortunate to locate a firm, Peter Martin Associates (PMA), that specialized in designing information systems for health care organizations. PMA spent over 200 man hours talking to staff, learning our case management process and integrating our conceptual needs into a software application, which has in turn spawned the two products FACTS and Perfect Match.

Program Implications

Training Development of the system has progressed in stages over a period of approximately two years. Modules were added as funding became available and design challenges were overcome. Accordingly, the training of staff has been an ongoing process. The majority of staff were initially reluctant to use the computer; many had never used a computer and perceived it as something difficult to learn. However, staff were prepared for the leap into technology because they were informed at their first interview for hire that learning to use a computer would be part of their duties. Also, all staff were involved in designing the system. They were

consulted before finalizing conceptual design and the organization of information on the screen.

PMA provided the initial training for staff and periodically conducts training as new features are added to the system. The program director is designated as the "system administrator" and receives extensive training on all aspects of the system. The director trains the clinical managers on features only used by the administrative staff, as well as all other modules. The family advocates are usually trained in groups of two, with sessions running no longer than two hours. Some staff are able to master operation of the system in a short time, while others take longer; none of the staff, however, is pressured into meeting certain performance standards. Every staffmember is allowed to learn at her or his own pace. This approach has led staff to feel confident that they will, over time, master use of the computer. At the time of this writing, all staff are currently trained and use the system. As new features become available and we acquire new staff, those already trained are used as trainers.

Service Efficiency Our goals in computerizing case management activities were twofold: 1) To reduce the time-consuming task of completing paperwork, thereby allowing more time to serve clients and increasing the number of clients who could be served; and 2) To have a mechanism for reporting key statistics needed to evaluate and monitor the program's efforts.

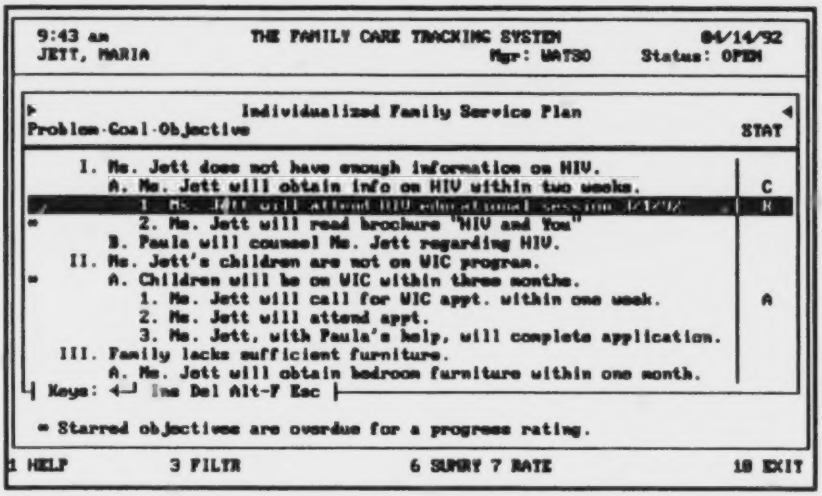
These goals have been met in many practical ways. Frontline staff, for example, are able to locate needed resources in record time. Rather than being hidden in the rolodex files of individual staffmembers, information on service agencies is shared continually over the network. Likewise, managers are able to complete time-consuming Quarterly Progress Reports and Case Closings with a few keystrokes, assembling the IFSP literally in seconds. The director is able to print out program statistics for virtually any information contained on the system. Reports can be

obtained on everything from caseload size by staffmember to demographics on open clients or all clients program-to-date, from family income sources to diagnosis frequency.

Collaboration We are currently having discussions with other human service organizations to develop a plan for networking both the Resource Directory and client tracking functions. Future plans include installation of FACTS at La Rabida Children's Hospital and Research Center to coordinate discharge planning and outpatient services with case management services. We are also working with Direction Service of Illinois, a statewide referral service, to create a central resource directory for the State of Illinois. In Chicago, we are looking at other agencies that could be used as demonstration sites to test a wide-area networking concept.

Human Service Capabilities

FACTS and Perfect Match As the development team began to network with other agencies and to explore the possible application of the CSS software in a wider context, the development effort ultimately led to the creation of two, not just one, software products. In demonstrating the software for a wide range of audiences over a period of two years, it became clear that for some agencies, a sophisticated information and referral capability was far more important than case management features; the latter, in fact, were at times irrelevant. To meet the specialized needs of agencies whose primary service is the gathering and dissemination of resource information--the classic example being the information and referral hotline--the developers decided to abstract the I&R module from the CSS software and spin it off as a separate software product, Perfect Match. While the **Family Care Tracking System (FACTS)** provides integrated support for both case management and information and referral, **Perfect Match** focuses almost exclusively on I&R. A brief synopsis of each product follows.


9:43 am
JETT, MARIA
THE FAMILY CARE TRACKING SYSTEM
Mgr: WATSO
04/14/92
Status: OPEN
Individualized Family Service Plan
Problem-Goal-Objective
STAT
I. Ms. Jett does not have enough information on HIV.
A. Ms. Jett will obtain info on HIV within two weeks.
C
1 Ms. Jett will attend HIV educational session 4/21/92
R
2. Ms. Jett will read brochure "HIV and You"
B. Paula will counsel Ms. Jett regarding HIV.
II. Ms. Jett's children are not on WIC program.
A. Children will be on WIC within three months.
1. Ms. Jett will call for WIC appt. within one week.
A
2. Ms. Jett will attend appt.
3. Ms. Jett, with Paula's help, will complete application.
III. Family lacks sufficient furniture.
A. Ms. Jett will obtain bedroom furniture within one month.
Keys: ↵ Ins Del Alt-F Esc
* Starred objectives are overdue for a progress rating.
1 HELP
3 FILTR
6 SUMRY 7 RATE
10 EXIT

FACTS : The IFSP Builder

FACTS was developed from the start to support the IFSP model of case management. It offers the following features:

- **In-depth Intake and Client profiles** capturing information on family structure, emergency contacts, medical status, income and entitlements, services needed, health and human service professionals associated with the family, birth events, risk factors

- **A full-featured IFSP Builder** allowing for entry of problems, goals and objectives and subsequent tracking of progress; ability to rate plan items both individually and as part of comprehensive period reviews; automatic flagging of IFSP items overdue for progress rating

- **Encounter tracking** capabilities

- **Word processing-style notepads** where narratives and other textual information can be maintained

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- **Strong security measures** to protect the confidentiality of client records

- **A full-featured Resource Inventory** able to capture information on each resource's services, eligibility requirements, intake procedures, geographical coverage, special facilities such as Braille and TDD, and more

- **Intelligent resource matching** based on client service needs, location, and demographics; flexible keyword search tools

- **Direct support for personalized mailouts** of resource information; agency-customizable letter and report formats

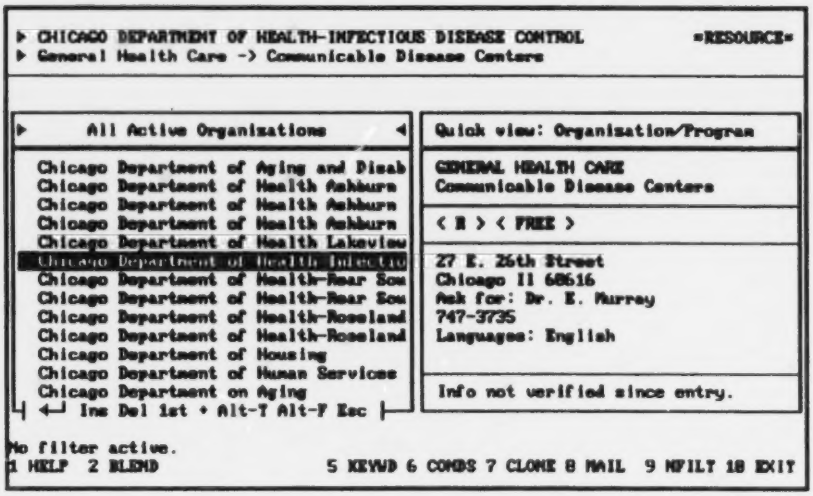
- **Support for a user-definable taxonomy of services** which can be used for extra-fast resource matching

- **Instant validation of data entries** against agency-maintained codebooks and historical records

- **A full set of standard reports** as well as strong support for user-defined reports

- **A flexible Query Builder** which enables agencies to develop highly specialized selection filters for any report, greatly extending the reach of the report libraries

- **Productivity aids** such as a pop-up calendar, onscreen area maps, and integrated electronic mail and help systems


▶ CHICAGO DEPARTMENT OF HEALTH-INFECTIOUS DISEASE CONTROL
▶ General Health Care -> Communicable Disease Centers
RESOURCE
▶ All Active Organizations ◀
Chicago Department of Aging and Disab
Chicago Department of Health Ashburn
Chicago Department of Health Ashburn
Chicago Department of Health Ashburn
Chicago Department of Health Lakeview
Chicago Department of Health-Rear Sou
Chicago Department of Health-Rear Sou
Chicago Department of Health-Roseland
Chicago Department of Health-Roseland
Chicago Department of Housing
Chicago Department of Human Services
Chicago Department on Aging
↵ Ins Del 1st + Alt-T Alt-F Esc
Quick view: Organization/Program
GENERAL HEALTH CARE
Communicable Disease Centers
< H > < FREE >
27 E. 26th Street
Chicago Il 60616
Ask for: Dr. E. Murray
747-3735
Languages: English
Info not verified since entry.
No filter active.
1 HELP 2 BLEND 5 KEYWD 6 COMBS 7 CLONE 8 MAIL 9 MFILT 10 EXIT

Perfect Match: The Resource Inventory

Perfect Match omits many of the FACTS case management functions while providing additional features useful to agencies which handle a high volume of informational calls. Key features include:

- **The Resource Inventory, Taxonomy of Services, Search and Mailout tools** described in the FACTS section above
- **An Inquiry Log** capable of displaying inquiries by date, status, caller, or client--all at the touch of a key
- **Tracking functions for client risk factors, disabilities and diagnoses**
- **Encounter tracking,** with agency-defined encounter types and sites
- **Client financial analysis** screen

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- **Instant validation of data entries** against agency-maintained codebooks and historical records

- **Narrative notepads** for every inquiry, caller, client, and organization; integrated word processing functions

- **Report, query and support utilities** similar to those in FACTS, as well as specialized features such as an autodialer

Capacities and Technical Specifications - FACTS and Perfect Match

Hardware

Both products are designed to run on fully IBM-compatible personal computers and network servers. They can also be run in conjunction with DOS-compatibility software in the UNIX PC-NFS and Macintosh environments. FACTS and Perfect Match are available in both single-user and network versions, and will automatically utilize up to two megabytes of extended memory for performance enhancement when available.

Security

All data is protected by a multi-tier security system including passwords and personal privilege levels. On networks, these security measures work hand in hand with security features of the network operating system.

Capacity

Items common to both FACTS and Perfect Match

Client records:	Unlimited, to hard disk capacity
Encounter records:	Unlimited, to hard disk capacity

Diagnosis records:	Unlimited, to hard disk capacity
Resource records:	Unlimited, to hard disk capacity
Taxonomy headings:	9,800
Narrative notepads:	16 pages per inquiry/client/caller
Distinct security levels:	99

FACTS only

Intake records:	Unlimited, to hard disk capacity
IFSP items per client:	67,000
IFSPs (all clients):	Unlimited, to hard disk capacity
IFSP rating records:	Unlimited, to hard disk capacity
Household member records:	Unlimited, to hard disk capacity
Medication records:	Unlimited, to hard disk capacity

Perfect Match only

Inquiry records:	Unlimited, to hard disk capacity
Caller records:	Unlimited, to hard disk capacity

Future Directions

With the formal release of FACTS and Perfect Match now complete, the development team is already at work on follow-on versions of both. Features slated for coming releases are:

- Graphics-based geographical resource matching, including the ability to superimpose transportation maps over area maps and support for definition of irregularly-shaped service areas

- Enhanced support for health maintenance tracking, screening and prevention activities
- Enhanced effort reporting
- Optional modules for tracking of HIV- and AIDS-related client information
- Advanced support for tracking of developmental delay testing
- A protocol for regional data definition and sharing
- Optional support for automatic call logging via new caller ID technology, where available
- Optional audio read-back features for visually impaired users

In addition, plans are underway to set up an information clearinghouse for the voluntary exchange of resource information collected by different agencies using FACTS and Perfect Match. These efforts grow from our firm conviction that information systems, when well designed and supported, can play a vital role in harmonizing the efforts of diverse agencies, improving not only cost-effectiveness but the very quality of service delivered to the client.

In Chicago, FACTS and Perfect Match are already acting as the vehicle for greater interagency communication and cooperation, helping to ensure that the limited resources available for human service efforts are used wisely and to maximum effect. Children's Support Systems intends to continue exploring the value of information technology for frontline service providers, building on the experience it has gained through conceptualizing and then implementing a complex information system.

Contact Information

For further information on Children's Support Systems, FACTS, Perfect Match, or the other topics discussed in this paper, contact:

Jacquelyn Vincson U'Deen
Director, Children's Support Systems
Woodlawn Social Services Center
950 East 61st Street
Chicago, IL 60637
(312) 324-9495
(312) 324-3571 FAX

Edward Hamlin
Principal
Peter Martin Associates, Inc.
2547 W. Leland Avenue
Chicago, IL 60625
(312) 478-2400
(312) 478-4009 FAX

TRACKING SYSTEM FOR AT-RISK AND DISABLED INFANTS: A MODEL FOR SERVICE COORDINATION

Presented by:

Duvon Winborne, Ph.D.
Director
Office of Educational Research & Development
University of Kentucky
Lexington, KY

TRACKING SYSTEM FOR AT-RISK & DISABLED INFANTS: A MODEL FOR SERVICE COORDINATION

by
Duvon G. Winborne, Ph.D., University of Kentucky-Lexington
E. Elaine Vowels, Ph.D., Commision of Public Health, Washington, D.C.

The D.C. Commission of Public Health initiated a project during the 1980s for the early identification, monitoring, and service delivery for at-risk and disabled infants. Planning procedures for the project began by convening a group of experts in fields related to early childhood development and healthcare. These experts established broadly the parameters and goals for an intervention that came to be known as "The D. C. Birth-to-Three Linkage and Tracking Project for At-Risk and Disabled Infants."

Through the involvement of professionals from various health-care and family-service agencies throughout the District, a set of specific objectives and time lines were established for the Birth-to-Three Project. The main objective of the Project was to establish a computerized system that would contain comprehensive data on disabling conditions for identified infants, as well as data on services received by the infants and their families. Ancillary to this main objective were those of facilitating case management, networking service delivery agencies, and supporting other District databases. Ultimately, information generated through the Birth-to-Three Project would be used collaboratively with various government agencies for planning long-term services (e.g., school programs, rehabilitation services, social interventions) for children with developmental problems during infancy.

CONCEPTUAL BACKGROUND

During the past 30 years, strategies for early childhood intervention have changed substantially in terms of focus and approach. The period from 1960 to 1970 produced several federally funded programs designed for three-year-old and four-year-old children. These programs were founded on the concept of modifiability of cognitive performance, and a belief that intervention could make a difference in improving developmental outcomes, particularly with regard to academic achievement (Karnes, 1969; Klaus & Gray, 1968; Levenstein, 1970; Weikart, 1967). Perhaps the principal goals of early intervention programs were to address the needs of children from low-income families who were disproportionately found to perform poorly in school and to improve prospects for successful socialization of high-risk children.

Most of the 1960s-era early intervention programs attempted to teach academic skills that were considered important to school success. Evaluations of these programs suggested that, imme-

diately following intervention, children from low-income families demonstrated higher performance on intelligence tests than similar children who were not involved in the intervention. However, within a year or two after entry into public schools, the intervention children were not superior on measures of cognitive ability (Brofenbrenner, 1975; Cicirelli, 1969; Haskin, Finkelstein, & Stedman, 1978; Revilin, 1978; White, 1973).

As a result of these findings, behavioral scientists intensified their arguments that early intervention programs were critical to cognitive (and affective) development and that children from low-income families were likely too far behind by age three or four to benefit from such interventions. They further argued that intervention programs might produce more stable gains in cognitive ability if implemented earlier in a child's life (Winborne, 1991). Subsequently, intervention programs were designed for addressing the needs of target populations during infancy.

Outcomes from early intervention programs during the 1960s and 1970s led to a series of new strategies for resolving problems that surfaced during early childhood. Despite controversies over the effectiveness of various interventions, broadband, nonspecific and wide-ranging programs aimed at children during early childhood, particularly infants, continue. Many of the newer programs have been developed through the impetus of Public Law 94-142 (Federal Registry, 1977) and the current focus of behavioral scientists on the biologically involved infant. Essentially, programs established during the 1980s reached earlier into childhood, to the infancy period, where factors other than social and economical conditions have been assessed as contributing to developmental problems. Clearly, professional roles take on new identities when intervention strategies are aimed at infants and toddlers. Rather than being implemented solely by those in the educational system, programs designed to address the needs of infants are multidisciplinary in nature, involving individuals from the fields of medicine, social work, psychology, and education.

The Birth-to-Three Project reflects this comprehensive approach to intervention for at-risk and disabled infants. Largely known as "tracking systems," interventions of this type combine the resources of several state and local agencies to engage in a comprehensive approach to addressing the needs of target children and their families. Using a data-based approach, the tracking strategy begins assessing infants identified at birth for various risk conditions, and follows these infants through various developmental stages and treatment programs (Meisels, 1985; National Center for Clinical Infant Programs, 1985).

The tracking-oriented intervention is basically one of facilitation. Moreover, a case management approach is used to assist with the placement of infants and very young children in appropriate services. Healthcare services, educational interventions, audiological services, and medical treatments are integral to these programs. The strategy is designed to ensure that a child is given the proper services based on identified needs (Winborne & Harris, 1991). A team of experts plot a service scheme for the child relegating responsibility to a single agency, but each child is given a prescription for services that best fit his or her needs.

SYSTEM DESCRIPTION

At the heart of the District of Columbia's Birth-to-Three Project is a computer system designed for managing data on at-risk and disabled infants and services provided to these target children. The computer system is comprised of database management software integrated with a microcomputer network. Although several software devices support the system, a customized application was developed to enable users to store, retrieve, and modify data on infants efficiently. Developed with a commercial software package, this customized application is flexible and may be expanded or modified with relative ease. The software package was selected on the basis of its technical integrity, market popularity, and prospects for commercial longevity.

A top-down structured approach was used for developing the customized application for the Birth-to-Three Project. This approach involved designing and developing each module in an hierarchical fashion, where major modules interact with and control subordinate modules. In essence, the major modules function as "task managers," with subordinate modules performing the more specialized tasks. This top-down structured approach allowed for testing and integration of new modules during development, while the overall system continued to operate. Each module was developed in accordance with technical specifications outlined during planning phases of the Project. Modules were written and tested with data designed to exhaust all its capabilities. Problems found in any particular module were located and corrected without interrupting the system's regular operation. This development strategy allows for easy modification of screens, rapid changes in input and output formats, and an efficient addition of fields as the needs of the Project change.

The hardware in the Birth-to-Three Project's computer system is a local area network of microcomputers. Conceptually, this type of hardware configuration consists of a main computer that serves all other computers in the network. Defined as the **file server**, this main computer contains all utility programs, data files, and application programs for the system. Although each computer in the network has processing capabilities, the other units ostensibly serve as **work stations**.

Communications with other microcomputers in the network are accomplished with a utility program and a set of communications boards installed within each microcomputer in the network. The system's utility software also provides security for all files by limiting access to users on a graduated-priority basis. That is, users may be restricted from entering the overall system or may be limited to designated files or data elements. Individual users may be added to the system as required and security levels may be changed as necessary by the system's manager. Infant data and other important information may be transmitted to and from the local area network through an external connection installed in the work station. This connection allows the Birth-to-Three Project to access mainframe computer systems for sharing information with other agencies in D.C. Also, there is the capability for dial-in access to the Project's computer system.

This computer configuration, both hardware and software, allows the Birth-to-Three Project

to maintain a controlled computer environment, while maintaining a capacity for growth and flexibility. The approach used in developing the system allowed for quick development without compromising quality, ready modification of system elements, and insurance against technical obsolescence.

REPORTING CAPABILITIES

Broadly, the capabilities for generating reports on services provided for at-risk and disabled infants are limited only by the availability of data. The system has immense flexibility in tailoring reports to meet various needs of service providers, administrators, policy makers, and others with an interest in this target population. A key element in the process of report generation is the ability of the software system to arrange cases in sort order for mathematical computations and information output. For example, the birth dates or birth weights of infants may used for sorting cases and then printing out only those cases that meet certain specifications.

One area of considerable interest to all professionals involved with the target population is a reporting of at-risk conditions found at birth and during other points of their first three years of life. Reports may be generated that summarize these various conditions in a number of creative ways. Conditions may be presented by cohort or some other criterion for grouping. Aggregates of these condition codes may be created to highlight the nature of factors contributing the conditions (e.g., environmental conditions, medical conditions, genetic conditions).

In addition, information from the database may be output in "raw" format for analysis by statistical software (e.g., SAS or SPSS). Statistics may be generated for addressing any number of research-oriented questions. This capability increases the potential for developing useful reports. Graphics software packages may be used to enhance reports and presentations. Based on statistical summaries, graphic displays may be generated for reflecting trends and patterns of child development and service delivery.

Clearly, the Birth-to-Three Project has tremendous capabilities for meeting the changing information needs of service providers and policy-makers in the District of Columbia. Data from the project may be managed, analyzed, and treated in a number of ways to produce useful reports on factors relating to the target population. This system will ultimately lead to improved healthcare and family services for at-risk and disabled infants within the District of Columbia.

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INNOVATIVE COMPUTER APPLICATIONS IN THE HEALTH AND DISABILITY FIELDS

COMPUTER TECHNOLOGY AND LEISURE SKILLS

Presented by:

Gordon St. Michel, M.P.H.
Assistant Professor of Occupational Therapy

Robert Cunningham, OTR/L
Instructor of Occupational Therapy
Eastern Kentucky University
Richmond, KY

COMPUTER TECHNOLOGY AND LEISURE SKILLS

ROBERT CUNNINGHAM, OTR/L & GORDON ST. MICHEL, MPH, OTR/L
EASTERN KENTUCKY UNIVERSITY
OCCUPATIONAL THERAPY DEPARTMENT

"Children who do not play come into adulthood ill prepared. They lack task and interpersonal skills, have no sense of their place in the world, feel unable to effect change on their environment, do not know what to expect, or what is expected. They are basically naive, and often angry."

Mosey (1986, p. 84)

Introduction

Leisure is an important part of everyday living, but a difficult concept to define and a difficult activity to find the time for. According to the literature, most authors define leisure as the opposite of work and agree that it is the time that one uses when one is not working (Cavanaugh, 1990; Mosey, 1986). In addition, there are several theories that state leisure is a complex phenomena influenced by economic, environmental, political, social and psychological components (Kaplan, 1975; Kraus, 1971; & Wade, 1985). The literature on leisure has one common element, stressing the importance of leisure within the context of living. The purpose of this paper is to present literature on the importance of leisure skills and how computer technology can be used therapeutically to develop and enhance leisure skills in the disabled population.

Literature Review

The literature on leisure is diverse. Articles range from current leisure trends to studies on the importance of leisure to a variety of ages and populations. This paper will discuss the effects of leisure on individuals throughout the lifespan, the importance and meaning of leisure, leisure classifications and the importance of leisure to the disabled.

The purpose of leisure can be viewed from many different perspectives, from the classical Greek view that leisure was the highest attainment to a different viewpoint that leisure is the unstructured use of time (Kraus, 1971). Leisure allows opportunity to

develop talents and interests. Leisure gives individuals a sense of control over their environment and contributes to personal satisfaction.

Viewing leisure as a lifelong process enables one to see the shifting purpose of leisure. As infants grow, play becomes a primary activity. Play is often defined as the work of children (Christiansen, 1991). Play facilitates sensory, motor, cognitive and psychosocial development. Through play, children develop skills that are later integrated into adult behaviors. Adolescents use leisure as a form of preoccupation and these skills are typically seen as an extension of school activities. The adolescent uses leisure for testing their skills, developing in the process an individual identity necessary for the transition into adulthood.

For the maturing adult, leisure takes the form of family and home centered activity for strengthening family bonds. Leisure becomes less home and family oriented for the older adult because these individuals have the opportunity to explore and engage in deferred goals and leisure interests (Cavanaugh, 1990).

The benefits of engaging in leisure activities are numerous. Throughout a lifetime, a person needs time away from work and other responsibilities. Involvement in leisure gives the individual time to make the departure from these responsibilities. Leisure is important because it offers psychosocial health by decreasing stress in the individual. Through an individual's inherent biological need to interact with the environment and use their sensorimotor systems, leisure influences physical health. Self-expression is enhanced with leisure because we can communicate verbally and non-verbally through the activities in which we engage. Lastly, through exploration of and participation in leisure activities, an individual is able to meet their basic needs and experience continual personal growth and development (Corbin and Tait, 1973).

The literature on leisure points out that there are several external factors that affect choice, use and meaning of leisure (Kaplan, 1975). Demographic variables such as age, sex and income influence leisure development. For example, society dictates the

proper age for a leisure pursuit such as attending a certain movie. The area in which a person lives may be a major factor affecting the types and uses of recreational and leisure facilities. Persons with a higher level of education seem to have an increased awareness of possible leisure activities in their community. Engagement in work sets a pattern of attitudes and moods which forces one to decide how to spend leisure time. The location of our work environment also limits or opens leisure possibilities. Finally, a person may use leisure to enhance their work skills (Kraus, 1971).

It must be remembered that leisure activities and skills are in the "eye of the beholder." Cooking a gourmet meal may be perceived as a leisure activity, but to a professional chef it is considered work (Cavanaugh, 1990). Therefore, leisure activities can be organized according to personal meanings. In other words, individuals rank leisure activities in terms of a high-low intensity along a cognitive, emotional and physical continuum.

By its very nature, leisure has strong bonds to our values and culture. Leisure is a personal construct and a part of our heritage. Leisure is characterized by choice and is usually shared with others who possess like interests. Because of the many factors affecting leisure, the choice of recreational or leisure activities is perceived as having limits or being limitless. Leisure activities provide enjoyment and a sense of personal gratification. When undertaken, leisure activities can be a source of personal and professional need satisfaction (Mosey, 1986).

Four categories emerge to classify most leisure activities (Cavanaugh, 1990). The four categories include: cultural, physical, social and solitary. To further delineate these categories, other authors have developed and used a systematic classification of leisure activities for evaluating an individual's leisure skills and for the development of remediation programs (Overs, 1971; Kautzmann, 1984). This classification has categories with specific leisure activities listed under each category. The taxonomy includes the following: games, sports and movement activities, nature activities,

hobbies, creative arts and crafts, entertainment, organizational activities and educational activities. It is important to note that within this taxonomy, each of these broad classifications of leisure activities can be placed into one or more of the four leisure categories. For example, dancing can be perceived as having cultural, physical, social and solitary qualities.

The occupational therapy profession takes a unique view of leisure. Play or leisure skills are delineated by the American Occupational Therapy Association's (AOTA) Uniform Terminology. Uniform Terminology is a method of defining and reporting occupational therapy services to third party payers and other health care professions. This document separates leisure into two areas, play or leisure exploration and play or leisure performance (AOTA, 1990). Play or leisure exploration refers to identifying interests, skills, opportunities and appropriate leisure activities. Play or leisure performance is the actual participation by the individual in leisure activities using their inherent physical and psychosocial skills. Physical and psychosocial skills include such abilities as motor, sensory, cognitive, social interaction and self-concept. One philosophical assumption of occupational therapy is that an individual must be able to balance leisure activities with work skills and activities of daily living. An imbalance in any of these skills, as the result of physical and psychosocial dysfunction, developmental disabilities and aging may suggest the need for remediation or intervention.

Before any therapeutic program can be implemented, a patient must be evaluated or assessed to determine strengths and limitations. Knowing what the problem is before choosing a solution is the first step a therapist would take. Assessment of play/leisure skills and performance can give a therapist clues to the patient's progress in or accomplishment of developmental life tasks. An assessment also helps a therapist to determine if the patient has a balanced lifestyle. The assessment of play/leisure skills can be accomplished through several self-administered questionnaires or checklists that

can be found in the rehabilitation literature (Matsutsuyu, 1969; Gregory, 1983; Kautzmann, 1984; & Asher, 1989).

One specific leisure assessment that is available to measure play/leisure is the Leisure Diagnostic Battery (Ellis & Witt, 1990). The Leisure Diagnostic Battery is a self-administered questionnaire developed to measure leisure functioning and provide a basis for determining remediation programming. Long and short versions are available for evaluating leisure functioning in youths and adults. An automated or computerized version of the instrument is also available and was developed to decrease the time required to take and score the manual version of the battery. In one study, the manual version and the computerized version were administered to adolescent psychiatric patients. The researchers found several interesting advantages of administering a computerized version of the Leisure Diagnostic Battery. The computerized version was as reliable as the manual version, was viewed more favorably, saved time in scoring, reduced scoring errors and took the same amount of time to complete as the manual version (Halberg & Olsson, 1989).

The value of administering a play/leisure assessment, whether manually or computerized, is to provide the therapist with ideas to plan activities to meet a patient's individual leisure interests and needs.

The Importance of Leisure to the Disabled

Barriers or constraints to involvement in leisure activities were previously discussed. Yet, one barrier that is not frequently mentioned in the leisure literature is a disabling condition. For persons with disabilities, leisure remains an important component for a balanced life.

Prior to the onset of an illness or disability, the individual has usually developed and invested time in establishing a balance of work, self-care and leisure skills. Illness or disability disrupts this balance. Time devoted to work and self-care activities may be increased or decreased because the individual may be unable to perform these tasks in

the usual manner. Often what remains in it's place is a disruption of the previously established balance. This disruption may force the individual to identify a solution to deal with the issue of time management. The exploration and development of leisure pursuits is one solution to regain the purpose and structure that work and self-care once occupied.

Trombly (1989) states that leisure activities can provide opportunities to redevelop competency and self-esteem, redevelop social relationships, maintain or increase strength and endurance and other physical gains made in the rehabilitation program. The difficulty with this process is seen in the ability of the disabled person to identify and match their interests and capabilities with the appropriate selection of leisure activities. One role of the occupational therapist is to collaborate with the patient in identifying their interests, make necessary adaptations for leisure participation and help identify those activities that will help in meeting individualized treatment goals.

Computer Leisure Applications with the Disabled

The current rehabilitation literature contains several technology related articles and clinical applications. Most of the literature cites clinical examples of computer technology used to increase independence in daily living skills or improve cognitive functioning. Very few articles discuss how the computer can be used to improve or enhance leisure skills. Ryan, Ryan and Walker (1989), in their text for the certified occupational therapy assistant, states that the use of computers to develop new leisure interests is virtually endless. Examples include: computer games that can be played alone or with others; computer programs that offer educational opportunities such as learning a foreign language; and word processing and graphic programs that allow creative abilities to be expressed.

Kautzmann (1990) discusses a project of how occupational therapy students used a computer to teach leisure skills to an elderly population. Her conclusion was that the

computer can be a beneficial treatment modality to increase leisure skills based on observations that this population had increased feelings of self-esteem and a sense of mastery over a new stimulus in the environment. In addition, the novelty of the activity caused participants in each facility to become engaged in the activity process.

The literature on computer applications with the disabled presents several advantages. First, the computer is an objective tool, meaning that a computer presents information in a sequential or standardized manner. This allows for effective data gathering and consistent treatment approaches with patients. Secondly, the computer can be adjusted to proceed at the patient's pace (Colby, 1980). Finally, the computer is a novel activity for some patients and the novelty leads to increased levels of motivation. The computer is not without its disadvantages. Computer technology is not amenable for use with some diagnostic categories or patients who are illiterate (Roberts, 1980). In addition, the computer can not recognize non-verbal communication and therefore will not intervene when the patient is experiencing signs of confusion or frustration. Finally, some patients fear technology and will not benefit from the introduction of this modality.

Brasile, Conway-Callahan, Dager and Klecker(1986) present conceptual models of computer applications from an administrative and programmatic perspective in the therapeutic recreation literature. The programmatic perspective presents a model of three specific categories. These categories include: Computer Assisted Treatment Services (CATS); Computer Assisted Techniques Toward Leisure Education (CATTLE); and Computer Assisted Recreational Programming (CARP).

Computer Assisted Treatment Services is the use of the computer as a treatment modality used to help in the treatment of individuals with disabilities. Examples include the use of software and alternative access devices that enhance such skills as problem solving, fine motor control, socialization and eye-hand coordination.

Computer Assisted Techniques Toward Leisure Education refers to the use of the computer for increasing an individual's leisure awareness. Specific examples include leisure value clarification and leisure resources. The authors are quick to point out that the therapist must spend time in developing these applications, such as building a data base of leisure resources available in a selected community.

Computer Assisted Recreational Programming refers to the use of computers for general recreational programming specifically for enjoyment and computer literacy. Examples include computer game competitions, graphic programs, and involvement in computer literacy classes.

Considering the computer's advantages and disadvantages, it is important to note that the computer is only one modality that can be used to achieve therapeutic goals concerning the leisure area.

Assessment of the Patient

Before introducing an individual with a disability to the computer or computer activities, an assessment should be completed by a qualified assistive technology team to determine the patient's specific needs and abilities to insure adequate access. Lee and Thomas (1990, p.18-21) refer to this process as the control assessment. The control assessment consists of nine stages that include the following:

1. Gather and analyze background information. Information regarding the patient is gathered from questionnaire completion, interview and medical chart review. It is recommended that a complete evaluation of the individuals physical and cognitive abilities be completed. The physical evaluation should include assessment of muscle strength, range of motion, endurance, sensation, visual/perceptual status and gross and fine motor control. The cognitive evaluation should include assessment of motor-planning skills, long and short term memory and cognitive processing. This information will aid in separating the patient's needs, abilities and constraints, as well as determining the features required in an access system.

2. Patient observation. The patient is observed in the performance of practical activities to obtain a complete clinical picture. This stage includes identifying the position from which the individual will access the computer.

3. Survey patient's skills. Based on data gathered from steps 1 and 2, the team determines potential selection techniques that the patient may use to access the computer.

4. Evaluation of ideal access system characteristics. This stage is dedicated to the systematic evaluation of the following variables: the input device, selection set, selection technique and application information. This is the most extensive and complex stage of the process due to the number of possible options with each variable.

5. Propose possible access systems. From data gathered, the assessment team can propose possible access systems for the patient. Systems are presented to the patient for trial, then the patient and assessment team collaborate to make a final access system decision.

6. Personalize the access system. In this stage the access system is modified or adapted to meet specific needs of the patient.

7. Patient training. The ultimate goal of this stage is training the patient to develop functional independence and control of the access system.

8. Implementation in the patient's environment. In this stage, the assessment team works with the patient to incorporate the access system into the patient's environment.

9. Monitor progress. As a final measure, assessment of the patient's progress should be made periodically. This is completed to note any changes in function that may be experienced by the patient. Modifications or adaptations are made as needed.

Computer Adaptations

For a person with a disability to access a computer, various adaptations are often required. Adaptations that can be made are grouped into hardware, software and peripherals.

Hardware is the actual computer and it's electronic parts (Crist, 1986). Adaptations in this area include installation of an adaptive firmware card or a speech synthesizer. The adaptive firmware card allows access to the computer through alternative methods if the disabled person is unable to access the keyboard in the typical manner.

Software is an application program that sends messages to the computer allowing it to perform specific functions (Crist, 1986). Software should be selected that meets the patient's individual needs. Selection of any software program is based on an analysis of the features and purposes of the software. Besides the analysis of software, Higgins & Schaude (1991) suggest that the therapist ask themselves the following questions: Are the instructions concise and easy to follow? Is the content valid? How much supervision, if any, is required? Can you enter your information into the program? Is feedback supplied to the user? and Is the software adaptable and gradable?

Peripherals are devices that are connected to a computer for a specific purpose, such as disk drives, monitors, printers and switches (Crist, 1986). Peripherals are especially important when addressing access issues with the disabled. Examples include various switches for alternative access and braille printers or monitors that meet the needs of persons with visual impairments.

In addition to the examples provided above, there are several multiple access systems commercially available. The KE:NX system, available from Don Johnson Developmental Equipment, is an example of the adaptive firmware card for the Macintosh computer. The system consists of software and a peripheral that allows for attachment of alternative keyboards and multiple switch access. Aid + Me, available

from Computability, is a similar version developed for IBM and IBM compatible computers .

Software Application

Following assessment and collaboration with the patient regarding their leisure interests and needs, the selection of appropriate software must be considered. There are several choices of public domain, shareware and commercially available software developed for the consumer. Most of these software application programs have therapeutic value and may be of interest to the person with a disability. Also, many of these software programs have options that allow the disabled user to grade the software to their level of function.

As previously stated, leisure activities maybe placed into the four categories of cultural, physical, social and solitary. These categories may also be used to differentiate types of software used for therapeutic purposes with the disabled. Cultural software may include such applications as foreign language tutors, music composition programs, and craft/graphic programs. Social software may include popular boardgames for multiple players or accessing electronic mail and bulletin boards via a modem for communicating with other computer users.

Software applications in the physical leisure category are not viewed in the typical manner. The physical leisure category is associated with those activities that involve physical activity. The disabled user, who is unable to participate in physical activities, may still express an interest in these types of activities. The use of software programs that simulate physical activities allow participation in a leisure interest in an alternative manner. Examples would include such applications as computer football, golf, hockey and other sports related software. The final category, solitary leisure activities would include any application program that the individual can use alone.

The above categories allow for a classification of types of leisure software. It should be noted that certain software may have application to more than one category.

For example, a software program such as computer football may be seen as having physical, solitary or social qualities. In addition, it is felt that the preceding software applications also apply to the programmatic categories of computer assisted treatment services and computer assisted recreational programming as conceptualized by Brasile, et al. (1986).

Conclusion

This paper has attempted to highlight the importance of leisure skills for all individuals, emphasizing the leisure needs of the disabled. In addition, issues of assessment including leisure interests and computer access have also been discussed. Based on a review of the literature and personal experience, it seems that computer applications for enhancing leisure skills fall into two broad categories, leisure education and leisure applications. Regardless of how a therapist uses the computer as a therapeutic modality, it is only through appropriate adaptations and thorough analysis of each software program that disabled users individual needs and goals can be met.

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USING LASER VIDEODISCS AND DVI TO DEVELOP VISUAL DATABASES

Presented by:

Ronald Thorkildsen, Ph.D.
Associate Director
Center for Persons with Disabilities
Utah State University
Logan, UT

Using Laser Videodisc and DVI to Develop Visual Databases

Ron Thorkildsen, Ph.D.
Matthew Dirks

Utah State University

An assistive technology (AT) device is any item, product, or piece of equipment, whether purchased off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities. Because of rapid advances in technology, AT devices are becoming more prevalent. Large database containing information about AT devices make it easier to locate needed AT devices. There is a need, however, to not only provide descriptions of AT devices, but to provide demonstrations of AT devices. Through demonstrations, a service provider or a consumer can observe AT devices being used by a person with disabilities.

This paper describes a possible means of providing easily accessible videotaped demonstration through the use of a new technology called video compression technology. We describe existing databases and the technologies necessary to supplement these databases with videotaped demonstrations.

Databases

Databases, such as ABLEDATA, provide a wealth of information about AT, including detailed descriptions, price, availability, and sources for purchase or rent. Computer software such as Hyper-ABLEDATA has made ABLEDATA readily accessible via micro computers. Increased emphasis on assistive technology prompted by the passage of PL 100-402 (Technology Related Assistance for Persons with Disabilities) has resulted in widespread use of the ABLEDATA database.

Also, 700 photographs of products and product sound samples have been added to the database (Hall and Vanderheiden, 1990). The photographs and sound samples are valuable because it is often difficult to visualize the appearance and function of a device. The sound samples are particularly critical with devices that use synthesized audio, which often varies greatly in quality.

Even though Hyper-ABLEDATA provides a great deal of useful information about AT, the ideal service to consumers is to have devices widely available for demonstration and tryout. This service is, however, not practical--the cost is prohibitive. Further, expending large sums of money on devices for demonstration instead of having them available for use by persons with disabilities is a wasteful use of limited resources.

A less desirable, but useful demonstration process is videotaping demonstrations of available devices. However, because there are over 16,000 different devices stored in the Hyper-ABLEDATA system, it would take an unwieldy number of videotapes to provide meaningful demonstrations of each device. The need, then, is to locate or develop feasible and cost-efficient ways of storing and accessing large amounts of video. Recent optical and digital compression technologies may provide the means to meet this need. Newly developed video compression techniques make it possible to store large amounts of information, and optical disc technology makes that information accessible. The following sections of this paper briefly describe optical technologies, compression technologies, and a potential method for developing a visual database.

Optical Technologies

Primary optical storage formats include CD-ROM, Laser Videodisc, WORM (write once read many), and erasable optical discs. All four formats provide a large storage capacity and have potential for storing visual databases. However, only CD-Rom and laser videodisc are discussed here. (For a description of all four formats, see Rizzo, 1989).

CD-ROM

CD-ROM, developed by Philips and Sony, is the most widely used optical storage medium. With a storage capacity of 650 megabytes of digital data, the CD-ROM is an ideal format for distributing large amounts of prerecorded data (Rizzo, 1989). CD-ROM is the optical storage medium for the Hyper-ABLEDATA system. An external CD-Rom player costs about $614. (For a detailed description of CD-Rom, see Lambert & Sallis, 1987)

Laser Videodisc

Optical laser videodisc is a storage medium primarily used to store audio and video in an analog format, although digital audio storage and retrieval is currently possible. Laser videodisc provides excellent video still frames and rapid access to audio and video material contained on a videodisc. Laser videodisc players cost between $400 and $1800. As with CD-ROM discs, laser videodiscs are produced from videotape at a mastering facility and cost approximately $2500 per side to master. Both CD-ROM and laser videodiscs are candidates for storing video demonstrations of AT devices. (For a detailed description of laser videodiscs, see Lambert and Sallis, 1987).

Compressed Video

Video compression is a technique used to convert video signals to a digital format and to greatly reduce (compress) the amount of data required to store video signals on a computer file. The data, being in a digital format, is then useable with a computer. Compression is necessary because one frame of uncompressed video requires approximately 500 kilobytes (kbs) of storage. Because video motion requires 30 frames a second, a 650 megabyte CD-ROM could store only 43 seconds of uncompressed video motion. Obviously, this is not a practical method of video storage. Video compression techniques, however, allow up to 76 minutes of motion video on a 650 megabyte CD-ROM. Transmission of video is also a problem. One frame of uncompressed video being transmitted at the average hard disc speed of 150 Kbs would take 3.3 seconds to transmit one frame. However, compressed video data can be transmitted at a speed sufficient to display 30 frames per second. Digital compression techniques provide a practical method of video storage and transmission. The two major video compression formats are Digital Video Interactive (DVI) and Compact Disc-Interactive (CD-I).

DVI

DVI is an audio/video, digital compression technology that allows full motion video through the use of a micro-computer. DVI relies on two computer chips: a pixel

processor and an output display processor. The chips compress the video, store it on a computer storage device, and then decompress it in real time for presentation.

A DVI system can store and retrieve digital data from a hard disc or any optical storage device. DVI is primarily designed for IBM PC's, but it can also be used with MacIntosh computers. DVI is capable of storing 72 minutes of full-screen, full motion VCR quality video on a CD-ROM disc. The disc can also store up to 44 hours of audio, 40,000 video still frames, or 650,000 pages of text or data.

Three different audio levels are available: five hours of FM quality stereo, 20 hours of mid-range monaural or 40 hours near-AM quality monaural. There are three different levels of still images: 5,000 very high resolution, 10,000 high resolution, or 40,000 medium resolution images. The motion video with audio also has three different levels: 72 minutes of full screen and full motion video, 4 hours of 1/4 screen full motion video, or 16 hours of 1/8 screen motion video.

DVI opens up new areas for multimedia. Instead of needing several different sources, all the media can be stored by a computer, allowing for fast response and interactive applications. However, designing for DVI is a complex procedure because it includes aspects of video and computer-based instruction.

There are several different authoring tools available to assist DVI development. For example, Authology, produced by American Training International, allows the developer to create DVI applications without the need for computer program abilities. Authology allows the user to integrate animations, audio/music, full-motion video, text, and graphics to create a custom interactive educational product. DVI also has a library of "C" commands or DVI tools that allow the user to import and compress video and audio.

DVI was originally developed at the David Sarnoff Research Center (formerly RCA Laboratories). In October of 1988, Intel acquired the DVI Technology Venture from General Electric and set up a development center using most of the people who currently are involved in creating DVI.

One limitation of DVI is that the final compression, which is similar to videodisc mastering, is done by Intel labs. Another limitation is that DVI is not currently adhering to the Multimedia PC standard, which may make it much more difficult for potential developers to plan marketing strategies. (For a detailed description of DVI, see Luther, 1991.)

CD-I

Compact Disc Interactive (CD-I) is a multimedia format designed by Philips. It was originally conceived as a simple "buy-and-play" alternative to CD-ROM because the

control computer is built into the player. Any CD-I disc bought anywhere in the world will play on any CD-I player regardless of the local television standard, (Fox, 1990). Currently, CD-I is being marketed as a home entertainment system.

The CD-I disc can contain data in five different formats. First, it can handle 300,000 pages of text. Second, it can handle four levels of sound, ranging from 16 hours of AM radio quality monaural to 1 hour of CD audio. There are 16 parallel audio channels, which means it can deliver a message in 16 different languages. Third, there are five levels of image, including natural still pictures and specially encoded animation sequences. Fourth, there is room for 72 minutes of full-frame motion video, which may be accompanied by FM quality monaural sound on a disc (Press, 1990). Full-frame motion is currently at 10 frames per second and 30 frames per second will be available by the end of 1992 (Multimedia and Videodisc Monitor, April, 1992)

The computer industry chose to support CD-ROM instead of CD-I. Philips and Sony worked with MicroSoft to devise a bridge between the two formats, called CD-ROM XA (extended architecture), allowing CD-ROM discs to be played on CD-I players (Fox, 1990).

Table I summarizes some of the characteristics of DVI and CD-I. (For a detailed description of CD-I, see Lambert

and Sallis, 1987.) The information in Table 1 summarizes the characteristics of DVI and CD-I.

Table 1

Characteristics of DVI	Characteristics of CD-I
Audio Ranges from 5 hours FM stereo to 20 hours mid-range monaural to 40 hours near- AM monaural 2 channels available **Video Stills** Ranges from 5,000 very high res. to 10,000 high resolution to 40,000 medium resolution **Motion** Ranges from over 1 hour full screen, full motion to, around, 4 hours 1/4 screen, full motion to, around 16 hours 1/8 screen, 1/2 frame rate **Text/Data** 650,000 pages	**Audio** 16 parallel channels available More than 19 hours possible Ideal for music and multilingual applications **Video** Able to display partial-screen full-motion video Capacity of 7,000 natural (photographic-quality) pictures 16 million color variations possible, 32,768 for user manipulated graphics **Text/Data** Text capacity of 300,000 typed pages (200-volume encyclopedia) Computer programming equivalent to more than 1,000 floppy disks

This table was adapted from Frenkel, 1989.

Multimedia Standards

The development of standards is a problem faced by developers of all new computer technology. Without standards, third-party software development is greatly inhibited. To solve this problem, multimedia developers are developing industry standards.

The primary goal in developing standards for multimedia is to determine the type of hardware necessary to run the multimedia application. The standards are critical for program developers to deal with the variety of hardware and software combinations.

Currently, there is one primary standard for the Multimedia PC. Polilli, (1992) indicates that the multimedia platform minimum hardware configuration includes the following:

- 80286 10 Mhz processor
- 2 megabytes of RAM
- a 30-megabyte hard disk
- 3.5 floppy disc (1.44-Mb)
- CD-ROM drive
- VGA video display
- keyboard
- a two-button mouse
- an IBM joystick interface
- sound board
- a microphone (Polilli, 1992).

This minimum configuration runs on MS DOS (MicroSoft Disk Operating System) and uses MicroSoft's Windows with Multimedia Extensions.

The standard was designed by the Multimedia-PC Marketing Council, a subsidiary of the Software Publisher's Association. The council includes MicroSoft, Tandy Corporation, AT&T Computer Systems, Fujitsu Ltd., CompuAdd Corporation, NCR, Philips Consumer Electronics, Ing. C. Olivetti & Company, Zenith Data

Systems, NEC Technologies, Media Vision, Creative Labs Inc., and Headland Technology/Video Seven (Polilli, 1992). If software is designed to meet these requirements, it may carry an MPC logo to let users know that it will run on any MPC platform. Nevertheless, many designers and users feel that processing power is required to make a multimedia tool effective (Polilli, 1992).

Visual DataBases

As part of a federally funded project to develop preservice training materials about AT, we are exploring the feasibility of using laser videodiscs to provide video demonstrations of AT devices (Thorkildsen, 1991). We refer to these videodisc demonstrations as video vignettes.

A video vignette is a short, self-contained video example of an AT device. Some vignettes contain demonstrations by a person with a disability on the use of an AT device. The use of vignettes on a videodisc will provide a method for the following: (a) seeing a large number of AT devices in use, (b) providing practical examples of device applications, (c) determining the benefit of devices and services for specific individuals, (d) expanding knowledge of AT and the interdisciplinary nature of its delivery, and (e) keeping abreast of new products.

Vignettes are selected from the videodisc through the use of menus which are based on a set of device characteristics. The development of the vignettes will help determine appropriate categories for grouping and coding vignettes to maximize their

accessibility and effectiveness. Several categories are currently being used (Vanderheiden, 1991; Scherer & McKee, 1989). For example, after a cataloging system has been developed and implemented, vignettes may be viewed by type of device, type of disability, or age of person with disability.

Currently, vignettes are available on (a) three types of lifting devices for entry into vans and busses, (b) an augmentative communication device, and the (c) IBM Phone Communicator System. Vignettes are currently being developed for the Eye-Gaze System, a series of low-tech devices, and a series of off-the-shelf switches.

Each side of a videodisc contains either 30 minutes of sound and motion or 54,000 still frames or a combination of both. Because sound and motion is limited, it is critical to limit the storage space required for each vignette. To minimize the space requirements and maximize information about the device, a protocol for developing vignettes has been developed. The protocol concentrates on identifying and presenting only the critical attributes of the system. The protocol guides decision-making about what can be described by text, what can be described in still frames and what requires motion and/or audio.

As an intermediate step, laser videodiscs are currently being used because videodisc players are readily available and relatively inexpensive. The players required for the video vignettes produced by the training project sell for approximately $600. Either DVI or CD-I, given their greater storage capacity

and flexible searching capabilities, are immensely more feasible for storing vignettes and will be used when readily available. We are currently developing a DVI development system and exploring the use of CD-I. A prototype DVI version of a set of vignettes should be ready for field testing by the end of 1992.

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INFORMATION KALEIDOSCOPE

INFORMATION KALEIDOSCOPE:

SYSTEMATIC APPROACHES TO DATA ACQUISITION AND UPDATE IN INFORMATION AND REFERRAL, OR "WHAT DO YOU MEAN, EXPECT A 10% RETURN RATE?"

Presented by:

Robert W. Bass, Ph.D.
Director
New England INDEX
Shriver Center
Waltham, MA

Systematic Approaches to Data Acquisition and Updating in I&R, or
"What do you mean, expect a 10% return rate?"

Robert W. Bass, Director
New England INDEX Shriver Center, Waltham, Massachusetts

Two years ago, New England INDEX conducted a survey of people with disabilities, their families, and professionals in the field to learn more about their experiences in seeking information on disabilities. Table 1 presents data on the perceived quality of the information they had received. The results do not speak well for information services. Briefly, the majority of respondents did not find the information accurate, up-to-date, or complete; in only one-quarter of the cases did the information match their needs.

Table 2 speaks to why this "information gap" may exist. We also surveyed information providers and one of the questions we asked concerned methods by which the providers kept their information up-to-date. Only about 25% of those responding had any method of systematically updating their information. On another question, 45% of the agencies reported that the lack of any standardized updating method was a major obstacle to providing I & R.

This paper presents one systematic approach, used by New England INDEX, to initially acquire data and to keep it up-to-date. In addition, cost factors for the use of this method are provided.

Initial Data Acquisition

We began with an approach first described by Donald Dillman (1975) for use in social science research. Dillman's method (shown on the left hand side of Table 3) was called the Total Design Method (TDM) and involves a number of carefully described steps beginning with a questionnaire booklet and cover letter individually addressed to each entity to be surveyed.
Subsequent steps involved a series of increasingly intensive steps, culminating with certified mail for those who ultimately do not respond.

There were several reasons why we felt it necessary to modify Dillman's method. First, the first class postage he prescribed had jumped from approximately $ .12 to $ .25 by the time we began our data collection. Secondly, use of laser-generated address labels was so time-saving that we felt it worthwhile to try this approach. Third, we felt that certified mail was too expensive and not as likely to identify agencies no longer in business.

The modifications we made are shown in the right-hand side of Table 3. In addition to the changes already mentioned, we used telephone calls as the ultimate follow-up. If the first call did not produce a response, then we simply called back in a few weeks and asked that the agency send us a brochure. Figure 1 shows the number of returns as a function of the specific intervention used.

Figure 2 shows the results of the overall data collection. The seemingly impossible outcome of more questionnaires received than mailed is attributable to the fact that many agencies identified more than one program or one site. When the return rate was calculated based on the percentage of agencies returning questionnaires, our rate was 96%.

Tables 4 and 5 show the costs incurred for materials and personnel respectively. Those figures are based on our operating procedures and costs of materials in the late 80's. The personnel costs do not include planning time, meetings, or supervision and therefore should only be taken as a guideline for the actual costs of the mailing per se.

Updating of data at INDEX occurs in two ways: proactive and reactive. In the proactive method, each agency is sent a copy of the information we currently have once a year. The Dillman procedure is generally used and our return rate is about 70%. The reactive method involves our immediate response to any information we receive from consumers, etc. regarding the accuracy of our data. Once any suspected error is detected, we call the agency in question to verify the information we have received and make the changes immediately. Over the past year 89% of our entries have been changed by the proactive or reactive methods.

We realize that other methodology may prove equally effective for other situations and that in some situations our methods will not yield the same results. Our belief is that whatever the approach, it is best if it is done systematically and if the outcome is monitored. Tracking return rates should help fine tune the methodology and help document your efforts to those who fund the project.

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Gould, K.E., 1990. Desirability and Feasibility of Information and Referral Systems in New England: Summary Report of Project by New England INDEX funded by the Administration on Developmental Disabilities.

TABLE 1

Perception of Quality of Information Sources (Yes)
By Users* from All States

Quality Indicator	*% Responses*
Accuracy: n = 1841	48
Up-to-date: n = 1892	37
Complete: n = 1868	22
Matches Need: n = 1879	25
Timely: n = 1862	39

*Primary Indicator

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TABLE 2

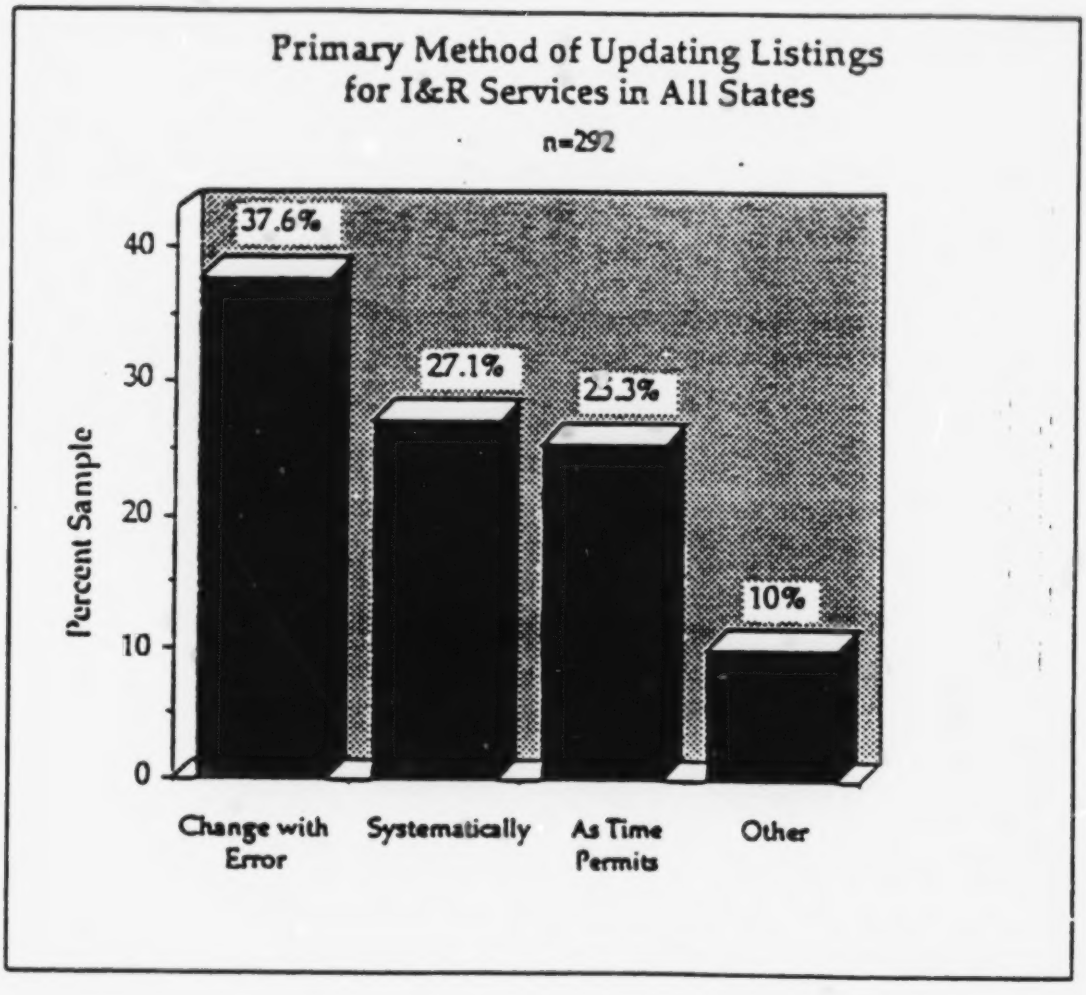

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TABLE 3

INDEX MODIFICATIONS TO TOTAL DESIGN METHOD

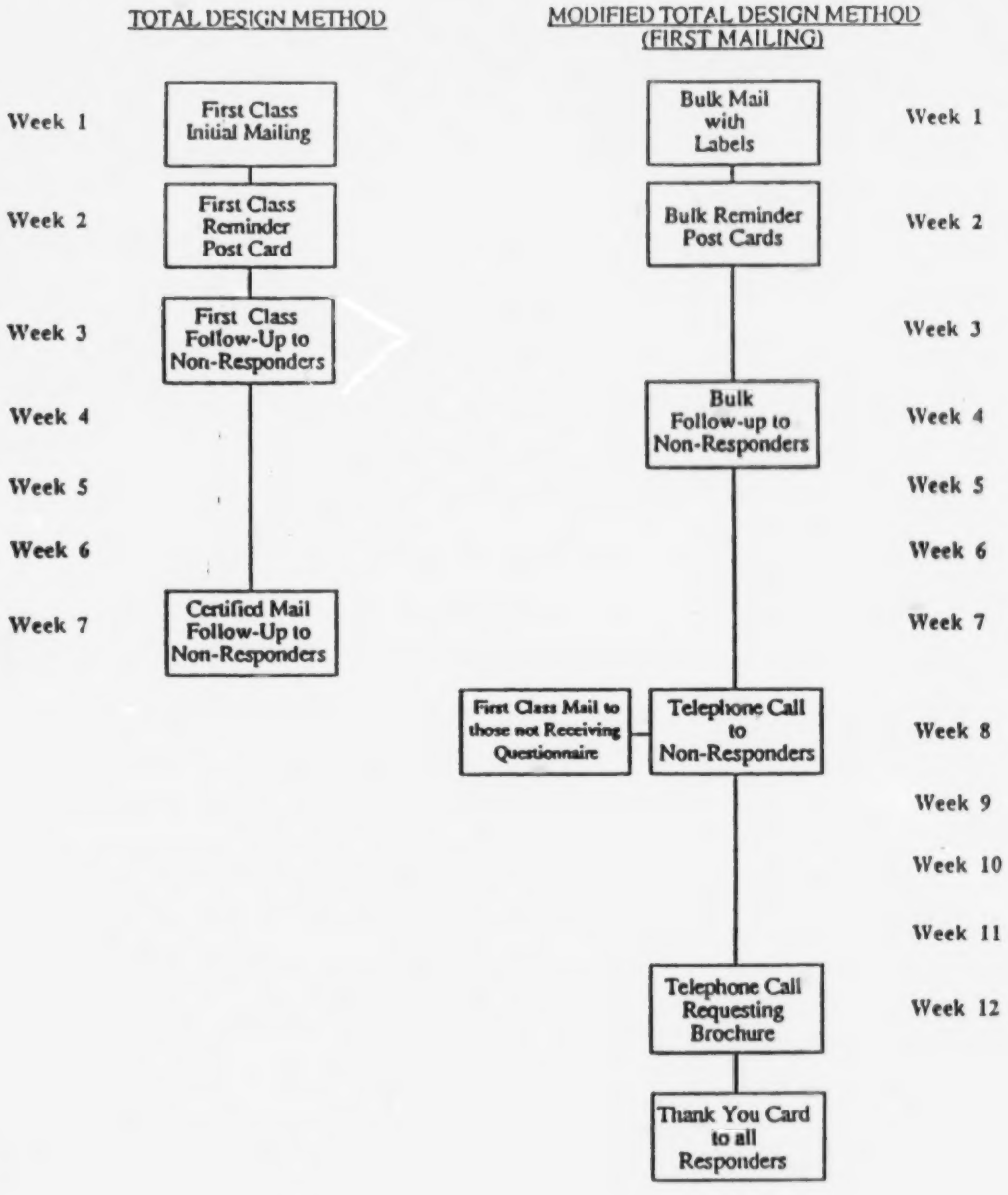


TABLE 4

Cost to Collect Information on a Single Program
(excluding Personnel Costs)

Postage:			
First mailing	.085	bulk	
Post Card reminder	.085	bulk	
Follow-up letter	.064	75 % of .085	
Thank you card	.140	first class	
Third mailing	.098	(25% at first class,0.39)	
Business reply mail	.390	average	
Total Postage	.862		.862
Printing:			
Envelopes (2)	.080		
Post Card (2)	.080		
Booklet	.130		
Brochure	.120		
Stationary	.040		
Taxonomy	.080		
Label	.090		
Laser Cartridge	.045	$45/3000 x 3 printings	
Total Printing Costs	.665		.665
Telephone:	.350	.70 x 50%	.350
TOTAL COSTS PER RECORD ENTERED			$1.877

TABLE 5

Time Required to Collect Information on a Single Program
(in minutes, based on data from 1612 records entered into computer)

Task	Time	Comments
Locate Directory	.298	8 hours total
Enter Program i.d.	2.000	estimate
Check data integrity	.223	6 hours total
Print letters & labels	.298	8 hours total
Signing & Packaging	1.710	measured
Reminder postcard	.200	signing & labeling = 6+6 = 12 sec
Second mailing:		
Printing	.223	6 hours total
Packaging	1.283	1.71 min x 75% (% requiring second mailing)
Telephone Calls	3.500	(3 min to get someone who "knows" 4 min to get info) x 50% (% requiring telephone calls)
Third Mailing	.425	1.71 mins x 25% (% requiring third mailing)
Extras--assembly, post office, bulk preparation	1.630	based on fixed time for any number - measured
Marking and i.d. in computer	3.000	estimate
Filing	1.000	estimate
Thank you card	.250	estimate
Data entry	10.000	estimate
TOTAL	26.040 minutes/record	

1612 records x 26.04 = 700 hours or approximately 17.5 weeks

Sample Personnel Costs (remember to include fringe!):

At $18,000 per annum = $3.75/record
At $22,000 per annum = $4.59/record
At $26,000 per annum = $5.42/record
At $30,000 per annum = $5.77/record

PROGRAM INFORMATION RECEIVED

as of 7/20/88

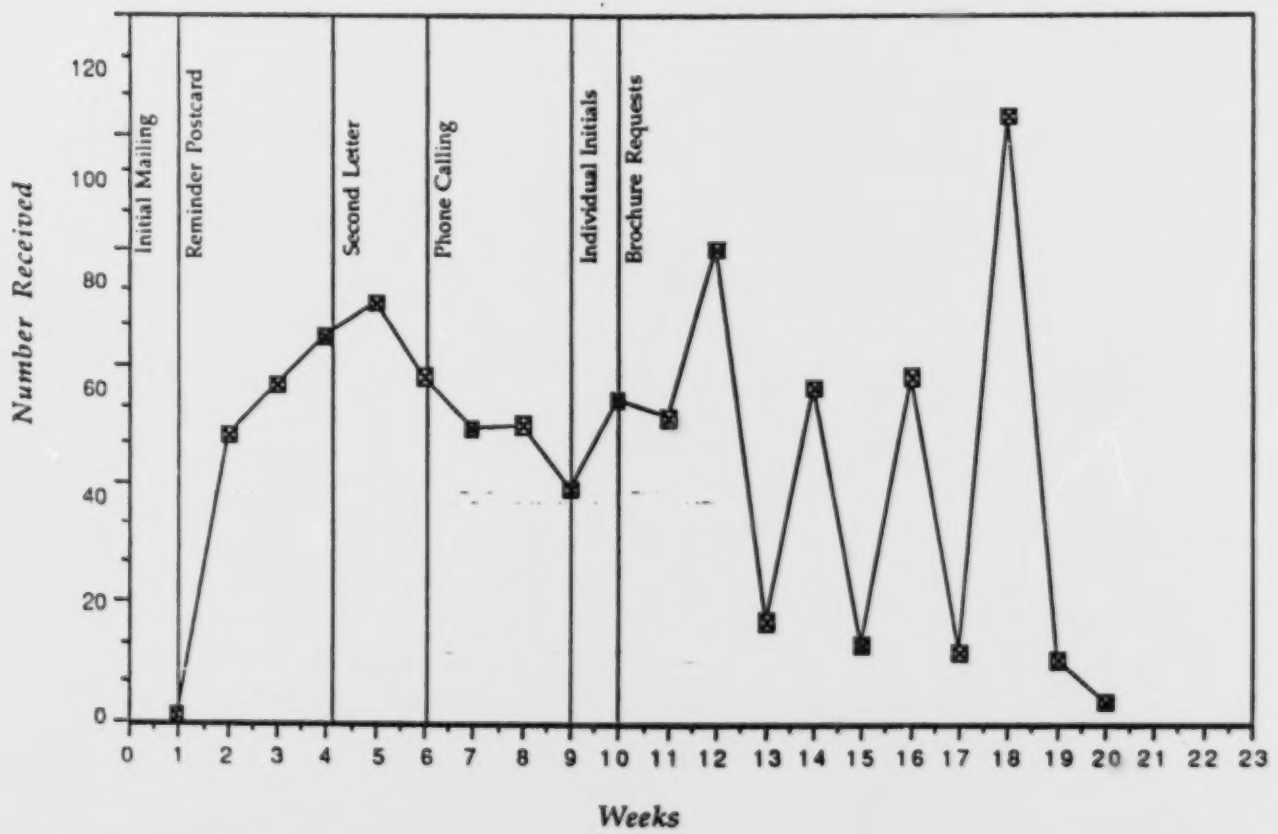


FIGURE 1

Information Acquired
New England INDEX Massachusetts System

October 17, 1989

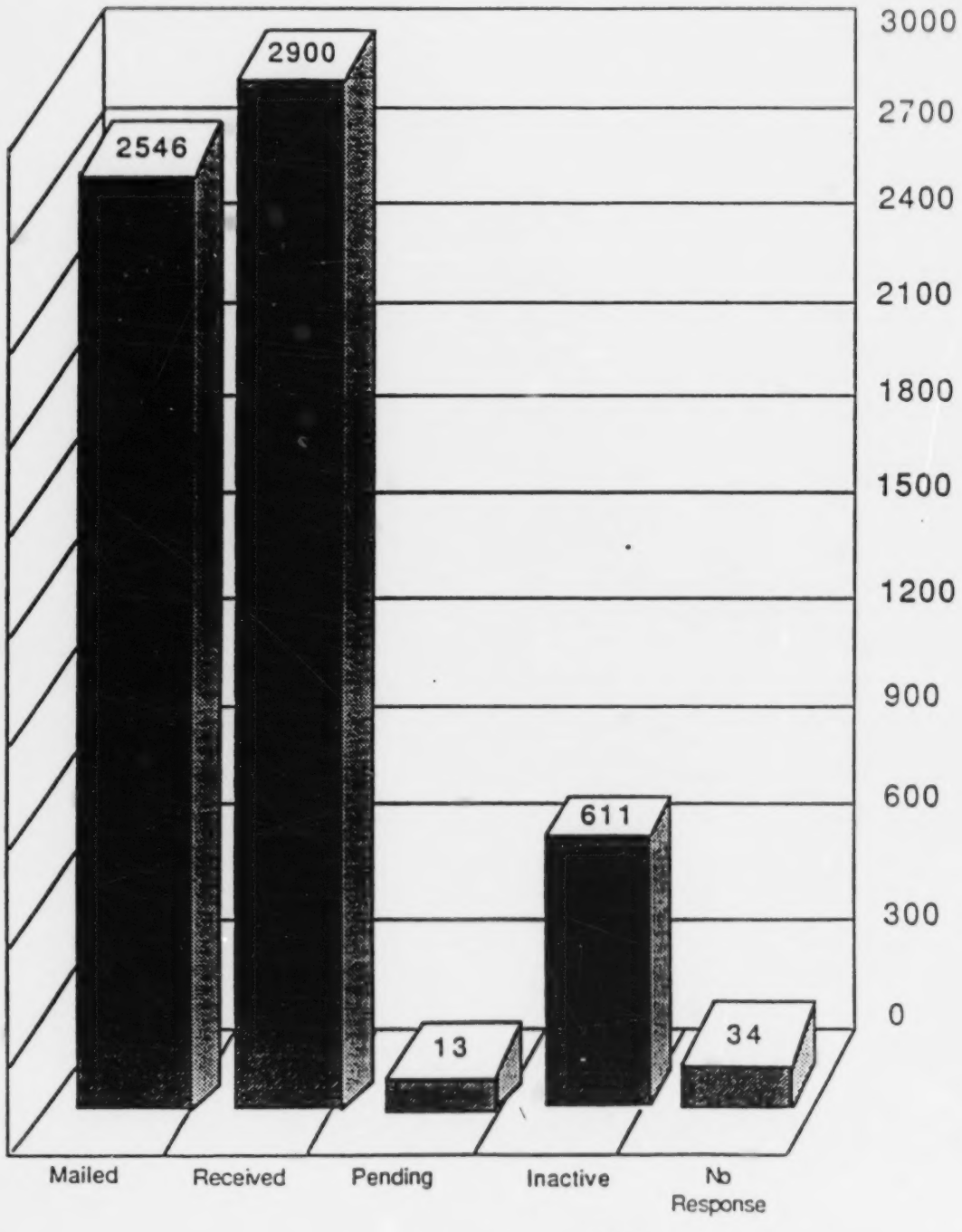


FIGURE 2

INFORMATION KALEIDOSCOPE:

PUBLICIZING YOUR INFORMATION AND REFERRAL PROGRAM

Presented by:

Clarice Eichelberger
DIAL Coordinator
Developmental Disabilities Council
Baton Rouge, LA

Publicizing your Information and Referral Program, *Clarice Eichelberger*, DIAL Coordinator, Developmental Disabilities Council, Baton Rouge, LA

Condensed information into a workshop format to encourage recording of what applies to participant's local situation. To be mailed here in miniature the actual handouts with additional related materials provided at the conference will be sent to you upon request from Clarice Eichelberger, DIAL, P.O.Box 3455 Bin 14, Baton Rouge, LA 70821.

SOME THING TO SHARE:

ATST NOW OFFERS A VERY ECONOMICAL 800 SERVICE

... CHECK WITH ... MANY DECIDE WHO GETS PUT ON THE COMMUNITY SERVICES PAGES - ASK IF YOU CAN BE CONSIDERED. IT DOESN'T COST ANYTHING.

IF YOU WANT TO HAVE AN EFFECTIVE AD CAMPAIGN ... AT LEAST MAKE THE MOST OF THE MONEY YOU SPEND BY GETTING THE MESSAGE OUT: " DON'T PREACH TO THE ... TEACH THOSE WHO DO NOT ALREADY ... ALREADY KNOW."

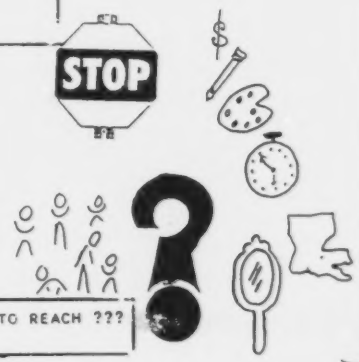
REMEMBER, NOBODY LIKES TO PICK UP SOMETHING UNATTRACTIVE. WE ARE ATTRACTED TO THINGS UNUSUAL, DIFFERENT, BUT PLEASING TO LOOK AT. NOW EVEN LITTLE YOU DO MAKE SURE IT LOOKS GOOD ENOUGH TO PICK UP.

... ALL HAVE A HISTORY AND CHILD ON YOUR ... BY A GOOD AD CAMPAIGN. IT SOUNDS ... YOU'VE INVESTED EFFECTIVELY WHEN YOU HEAR PEOPLE SAY "YA'LL BEEN AROUND FOR A WHILE NOW, HUH?" OR "OH YEAH I SAW YA'LL'S COMMERCIAL ON TV!" (PARDON THE VERNACULAR)

... ALWAYS APPRECIATE YOUR HELP AND ALSO APPRECIATE YOUR PUBLIC IMAGE REINFORCING THE REFERRAL THEY MAY HAVE GIVEN TO CONSTITUENTS TO CALL YOU. THEIR RESPECT OF YOUR PROGRAM STRENGTHENS YOUR POSTURE IN BOTH LEGISLATIVE AND BUDGETARY EFFORTS.

... YOUR PROGRAM HAVE BUDGET LIMITATIONS ... ALSO ARE FEELING A GOOD PEA ON YOUR PROGRAM ... HAVE PROVIDED AN OUTLET TO CALL AND ASK OF YOU, "CAN WE USE YOUR NUMBER AS OUR 800 AND WE ... SOLD PAY FOR THAT SERVICE?" THIS CAN ... IF YOU DON'T GENERATE YOUR OWN FUNDS ... A REFERRAL OR EXPANSION OR IT CAN ... ALLOW THE OTHER AGENCY TO PROVIDE MORE ... SERVICE OF OTHER TYPES SINCE THEY HAVE ... WELL IN HAND. WE ALL FEEL GOOD WHEN WE ... NEED TO AVOID REINVENTION OF THE WHEEL.

Considerations:



MONEY - HOW MUCH CAN YOU SPEND???
EVEN A LITTLE BIT, IF SPENT WISELY, CAN MAKE AN IMPACT ON YOUR AD EFFORTS.
MESSAGE - WHO CAN WRITE SENSITIVE COPY FOR A BROCHURE, FACT SHEET, REPORT???
VISUALS - DO YOU HAVE ARTISTIC SKILLS???
WE ARE ATTRACTED TO ATTRACTIVE PIECES.
TIME - DO YOU HAVE ENOUGH TO DO IT WELL???
A CAMPAIGN INCLUDES CONCEPT, DESIGN, WRITING PRODUCTION, MARKETING, DESSIMINATION ???
DIVERSITY - CONSIDERATION NEEDS TO BE GIVEN TO THE SCOPE OF CULTURES, ETHNICITIES, AGES, ISSUES OF CONCERN, AVAILABILITY OF PROVIDERS (PUBLIC AND PRIVITE)
IMAGE - WHAT IMAGE DO YOU WANT PEOPLE TO HAVE OF YOU/YOUR PROGRAM????

AUDIENCE - WHO ARE YOU TRYING TO REACH ???

Wise

... ALL THE ... YOUR THOUGHTS ON THE ITEMS ABOVE. TALK TO OTHER AGENCIES THAT ARE USING PROFESSIONAL PR OR AD AGENCIES

BEST COPY AVAILABLE

COMMUNICATIONS

MESSAGE & IMAGE

BE AWARE OF CARRIER MESSAGES AND IMAGES

ARE THEY APPROPRIATE FOR THE STATES?
ARE THEY SENSITIVE TO YOUR CULTURES?
CAN YOU AFFORD THEM? THE COSTS THEY CARRY DO NOT INCLUDE "PAINTING" IT WITH YOUR IDENTIFYING TAG (NAME AND PHONE CONTACT INFO) & COPIES THAT NEED TO BE SENT TO YOUR MAJOR MARKETS

Integrity (maintain control)

MAINTAINING ACCURATE INFORMATION, BEING ACCESSIBLE TO CALLERS, WRITERS, AND COLLEGUES, CONSTANTLY GROWING AND BEING EXCITED ABOUT THE I&R BUSINESS; OUTREACHING, EXPANDING, BEING WHAT YOU SAY YOU ARE, DOING WHAT YOU SAY YOU DO; RESPONDING IN AN APPROPRIATE AND AS COMPREHENSIVE A REFERRAL AS YOU CAN MAKE TO ALL LEGITIMATE REQUESTS ARE THE CHARACTERISTICS OF SERVICE INTEGRITY.

AN EFFECTIVE AD CAMPAIGN SHOULD PROJECT YOUR PROGRAM IN THIS LIGHT.

Collaborate
Collaborate
Collaborate
Collaborate

DIAL ♡s

- OFFICE OF ELDERLY AFFAIRS
- EPILEPSY BOARD OF DIRECTORS
- DEPT OF EDUCATION - SPEC ED
- DISABILITIES PREVENTION PROJECT
- MATERNAL AND CHILD HEALTH
- FAMILIES HELPING FAMILIES
- AGENT ORANGE ASSISTANCE PROJ
- EXTRA: GROCERY BAG (N.O.)
  N.O. CITY BUS
  KROGER BAGS (TEX, LA)
  BUS STOP BENCH

→ SOUTH CENTRAL BELL
→ SOCIAL SECURITY ADM
→ STATE MEDICAID APPLICATION

IF you build it good, they will come — and they will help with the public awareness efforts

BE CREATIVE, ASSERTIVE COOPERATIVE AND EFFECTIVE

COLLABORATE
BIGGER BANG for $

Long term

Telephone 800 pointer-system

Community service pages

Public awareness is Public Education

- ✓ Many are mandated to do;
- ✓ Breaks the traditional mode of audience;
- ✓ Creates further opportunities;
- ✓ Builds history & credibility;
- ✓ Strengthens agency posture;
- ✓ Helps attract sources of generated-funds.

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MONEY - HOW MUCH CAN YOU SPEND???
EVEN A LITTLE BIT. IF SPENT WISELY,
CAN MAKE AN IMPACT ON YOUR AD EFFORTS.
MESSAGE - WHO CAN WRITE SENSITIVE
COPY FOR A BROCHURE, FACT SHEET, REPORT???
VISUALS - DO YOU HAVE ARTISTIC SKILLS???
WE ARE ATTRACTED TO ATTRACTIVE PIECES.
TIME - DO YOU HAVE ENOUGH TO DO IT WELL???
A CAMPAIGN INCLUDES CONCEPT, DESIGN, WRITING
PRODUCTION, MARKETING, DESSIMINATION ???
DIVERSITY - CONSIDERATION NEEDS TO BE GIVEN
TO THE SCOPE OF CULTURES, ETHNICITIES,
AGES, ISSUES OF CONCERN, AVAILABILITY OF
PROVIDERS (PUBLIC AND PRIVITE)
IMAGE - WHAT IMAGE DO YOU WANT PEOPLE TO HAVE
OF YOU/YOUR PROGRAM????
AUDIENCE - WHO ARE YOU TRYING TO REACH ???

LIST OUT ALL YOUR THOUGHTS ON THE ITEMS ABOVE.
TALK TO OTHER AGENCIES THAT ARE USING PROFESSIONAL
PR OR AD AGENCIES

BE-WARE OF CANNED MESSAGES AND IMAGES

ARE THEY APPROPRIATE FOR YOUR STATE?
ARE THEY SENSITIVE TO YOUR CULTURES?
CAN YOU AFFORD THEM? THE COSTS THEY
QUOTE DOES NOT INCLUDE "FIXIN" IT WITH
YOUR IDENTIFYING TAG (NAME AND PHONE
CONTACT INFO) NOR COPIES THAT NEED TO
BE SENT TO YOUR MAJOR MARKETS

INTEGRITY

MAINTAINING ACCURATE INFORMATION,
BEING ACCESSIBLE TO CALLERS, WRITERS,
AND COLLEGUES, CONSTANTLY GROWING AND
BEING EXCITED ABOUT THE I&R BUSINESS;
OUTREACHING, EXPANDING, BEING WHAT YOU
SAY YOU ARE, DOING WHAT YOU SAY YOU
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MAKE TO ALL LEGITIMATE REQUESTS ARE THE
CHARACTERISTICS OF SERVICE INTEGRITY.

AN EFFECTIVE AD CAMPAIGN SHOULD PROJECT
YOUR PROGRAM IN THIS LIGHT.

BEST COPY AVAILABLE

SOME THINGS TO SHARE:

AT&T NOW OFFERS A VERY ECONOMICAL 800 SERVICE

THE TELEPHONE COMPANY DECIDES WHO GETS PUT ON THE COMMUNITY SERVICES PAGES - ASK IF YOU CAN BE CONSIDERED, IT DOESN'T COST ANYTHING.

IF YOU WANT TO HAVE AN EFFECTIVE AD CAMPAIGN OR AT LEAST MAKE THE MOST OF THE MONEY YOU SPEND ON GETTING THE MESSAGE OUT: " DON'T PREACH TO THE PEOPLE IN CHURCH!" REACH THOSE WHO DO NOT ALREADY KNOW ABOUT YOU.

REMEMBER, NOBODY LIKES TO PICK UP SOMETHING UNATTRACTIVE: WE ARE ATTRACTED TO THINGS UNUSUAL, DIFFERENT, BUT PLEASING TO LOOK AT. HOW EVER LITTLE YOU DO MAKE SURE IT LOOKS GOOD ENOUGH TO PICK UP

YOU CAN BUILD A HISTORY AND BUILD ON YOUR INTEGRITY BY A GOOD AD CAMPAIGN. IT SOUNDS LIKE YOU'VE INVESTED EFFECTIVELY WHEN YOU HEAR FOLKS SAY "YA'LL BEEN AROUND FOR A WHILE NOW, HUH?" OR "OH YEA! I SAW YA'LL'S COMMERCIAL ON TV!" (PARDON THE VERNACULAR)

LEGISLATORS APPRECIATE YOUR HELP AND ALSO APPRECIATE YOUR PUBLIC IMAGE REINFORCING THE REFERRAL THEY MAY HAVE GIVEN TO CONSTI-TUENTS TO CALL YOU. THEIR RESPECT OF YOUR PROGRAM STRENGTHENS YOUR POSTURE IN BOTH LEGISLATIVE AND BUDGETARY EFFORTS.

OTHER PROGRAMS HAVE BUDGET LIMITATIONS ALSO AND SEEING A GOOD PSA ON YOUR PROGRAM MAY PROVIDE AN ENTRE TO CALL AND ASK OF YOU, "CAN WE USE YOUR NUMBER AS OUR 800 AND WE COULD PAY FOR THAT SERVICE?" THIS CAN HELP IF YOU MUST GENERATE YOUR OWN FUNDS FOR OPERATION OR EXPANSION OR IT CAN ALLOW THE OTHER AGENCY TO PROVIDE MORE SERVICES OF OTHER TYPES SINCE THEY HAVE SAVED ON I&R. WE ALL FEEL GOOD WHEN WE HELPED PREVENT REINVENTION OF THE WHEEL.

INFORMATION KALEIDOSCOPE:

GETTING THE WORD OUT: PUBLICIZING YOUR INFORMATION AND REFERRAL SERVICE

Presented by:

Duane Gimbel, B.S.
Information, Referral, Outreach & Training Coordinator
MonTECH Program
Rural Institute on Disabilities
The University of Montana
Missoula, MT

Getting the Word Out:

Publicizing Your Information and Referral System

by Duane Gimbel

Studies across the country have shown that people do not know how to find and access services. This is why United Ways have started First Call for Help services, the Administration on Aging made information and referral a top priority in its Eldercare campaign and the Technology-Related Assistance for Individuals with Disabilities Act of 1988 began statewide I&R programs to help people find assistive technology devices and services.

Yet, marketing studies show that no matter how often we put our message out to the public, most people will not pay attention until they actually need a service. Just because you did a media blitz when you first announced your service, don't expect people to remember you a year, or even a month, down the road. Public relations efforts must be on-going.

If your phone lines are busy, so are the staff. Public relations are usually given a low priority. But rest assured, some of the most effective promotions come from non-staff. Consumers and those who care for them can deliver a potent message for you. If your service is doing what it is supposed to, those you've helped are telling their friends and colleagues about you. Why not tap into this energy to spread the word more widely? Establish a public relations committee or task force and give them the freedom and mission of promoting your service.

First, contact other specialized and generic I&R services in your area to let them know how to make referrals to you. Many

communities, states or regions have professional I&R groups that you'll want to be networking with. (To find the names of other I&R services and professional groups, contact the Alliance of Information at Referral Systems, P.O. Box 3546, Joliet, IL 60434 or call 815-744-6922.) Make sure your Chamber of Commerce knows about you. People moving into an area often contact the Chamber to find out about services. Then start contacting service organizations who serve the same target audience(s) as you.

Many people use the telephone book as their first source of information. If your local phonebook does not have "Community Information Pages", contact the telephone company to find out why. Work with other I&R providers in contacting your Public Service Commissioner to convince the telephone company to publish such a directory. AIRS can be a valuable resource in doing this. Be sure your number is included in the white pages and put money aside for some yellow pages advertising.

The Federal Communications Commission (FCC) requires all radio and television stations to air public service announcements (PSA's) free of charge. Check with your local stations for guidelines. Most will want something that can be read over the air in 30 or 60 seconds (read your message aloud and time it before submission). Cable stations will run messages at the bottom of the weather stations or on the community access channel. Don't forget to include your telephone number on all messages. Many stations with "noon shows" or other types of interview format are looking for guests. Your consumers and those who care for them can add the personal interest touch many producers search for.

Many newspapers run community events columns or allow non-profit organizations to announce services in bulletin board formats. Often times, newspapers will run a story about a new service in town but you are going to need a special event or human interest story to get repeat coverage. When you're sending your PSA to radio and television stations, send a copy to your local newspapers. Many organizations publish their own newsletters. Use them to announce your service!

Utility companies sometimes put fliers about organizations in with their monthly bills. Or the local grocery store prints a message about a service on their bags. This usually happens because someone working for the utility or business has a connection to the organization being heralded. Check with your consumers. Whose family members work where? What kind of clout do they have with the marketing department?

Billboards cam be very inexpensive, yet effective. Sign companies sometimes donate the board space, especially after elections when they want to get political messages covered (particularly losing issues) and they don't have enough advertisers.

When making presentations, include your consumers and those who care for them. People get tired of hearing professionals talk about their wonderful services, often viewing the speaker as a braggart. If you must talk, stick to the essentials. Let those most affected by your service be your spokesperson.

When publicizing, remember who your audience is and how best to reach them.

Getting the Work Out:

Publicizing Your Information and Referral System

I. Establish Public Relations Committee or Task Force
   A. Utilize consumers and people who care for them

II. Contact other I&R's in your area
   A. Check the telephone book
   B. Contact Alliance of Information and Referral Systems
      P.O. Box 3546
      Joliet, IL 60434
      (815) 744-6922
   C. Notify Chamber of Commerce, United Way, other organizations with similar audience

III. Work with the telephone company
   A. Utilize "Community Information Pages"
      1. Work with other I&Rs and Public Service Commissioner
   B. List in white & yellow pages

IV. Public Service Announcements on radio & television
   A. Contact stations for format (30-60 second spots)
   B. Utilize cable t.v. weather stations & community access channels
   C. Television interviews - personal interest

V. Newspapers & newsletters
   A. Include in PSA mailings
   B. Publicize using community events bulletin boards
   C. Human interest stories
   D. Use other organizations' newsletters to your advantage

VI. Fliers in utility bills & on grocery bags
   A. Use your connections - employed family members of consumers

VII. Billboards
   A. Free space after elections

VIII. Speaker's Bureaus
   A. Stay out of the limelight
   B. Utilize those most affected by your service to spread the word

for more information contact: Duane Gimbel
MonTECH Program
Rural Institute on Disabilities
The University of Montana
634 Eddy Ave.
Missoula, MT 59812
(406) 243-5676

INFORMATION KALEIDOSCOPE:

DEVELOPING INFORMATION AND REFERRAL SOFTWARE, IT'S A PEOPLE PROCESS

Presented by:

George Jones, M.A.
Director of Software Development
New England INDEX
Shriver Center
Waltham, MA

DEVELOPING INFORMATION AND REFERRAL SOFTWARE: IT'S A PEOPLE PROCESS

George H. Jones, M.A.

Computerized database systems are a natural match for agencies involved in information and referral activities. If designed well and implemented correctly, computer technology can help agencies to operate more efficiently and provide better services to their consumers. However, this technology should not be construed to be anything more than what it actually is: a tool that serves the system. What is the "system"? For information and referral (I&R) the system is a set of inter-related processes whereby: 1) data is methodically collected, 2) information is shared with those who need it, 3) existing data is updated and new data is added, and 4) consumers are routinely made aware of the existence of the service. Well designed software applications can assist in all of the above activities, but by far the most important ingredients of the system are the people who drive the process. The same is true for the development of the database software. The actual programming of the software takes a back seat to the importance of careful initial planning and the involvement in the development process of the people who will ultimately be implementing the system. This paper will address the entire development process, with a focus on how to involve the eventual users of the system at every step.

Why Develop Your Own?

For both public and private organizations, finding the right software application for the job remains a challenge. With the exception of those sectors such as accounting, where operations are standardized, pre-written software applications that are specific to the needs of an agency are often difficult to locate. Even when pre-written, task specific software applications can be found, there frequently seems to be something about the software that does not quite meet the needs of the agency or that would be better if changed. No pre-written software can anticipate nor understand all of the needs of your organization. As well, no software is ever really "finished". Over time the needs of an agency may change, and the more one uses a software application the more uses one finds for it. Having a software application custom tailored to one's particular requirements has the distinct advantage of ensuring the "best tool for the job". It ensures that the software fits the way you do business rather that forcing you to modify your

operations to the requirements of the software. Finally, the most important reason for considering the development of customized software is that the investment in staff and capital resources is too great to risk the implementation of a system that is not adequate to the needs of the agency and/or not accepted and therefore not utilized efficiently by agency staff. There is no better way to ensure acceptance of a system than the involvement of users in all stages of the development process.

The Development Process

Over a period of time, a protocol has evolved for developing software applications. This system development cycle emerged from the development of mainframe-based systems and while the basic sequence of these steps remains valid, the tools available to implement them have changed. Microcomputers and extremely fast database management systems (DBMS) have altered the pace and flexibility of the development of software applications. A process that once required the creation of a detailed and highly technical written design specification is now often replaced with a process known as "rapid prototyping" in which a series of working prototypes of components of the system are provided to the intended system users for their evaluation and comment. The idea here is that it is better to show you how the software will work rather than attempt to tell you via a written document. The steps of this process are shown below. Let's look at them in some detail.

Table 1: Rapid Prototype Model
1) Planning/Analysis Stage
2) User Requirements Definition
3) Prototyping/User Feedback
4) Implementation

1) The Planning/Analysis Stage

This first step is the most important of the whole development process. It is the foundation upon which the entire system must stand. In most cases, the failure of database software can be traced to poor planning rather than poor implementation. Do not rush through this stage nor underestimate the effort needed. The work done here determines the content and complexion of the User Requirements Definition document and subsequent prototypes. It is more time and cost efficient to make design changes here than when the project has progressed to later stages. Here are some suggestions for the planning stage:

a) The Feasibility Study: The feasibility study ensures that developing a computerized I&R system is both necessary and practical. Will it meet an identified need or solve an identified problem? In some cases, the answers to these questions are influenced by legislative mandates or requirements external to the agency. Other feasibility issues include technical, cost, and schedule feasibility. If there is little or no computer system experience within the agency, outside consultative assistance may be necessary.

b) The Work Group: Choose your work group carefully. Who will be involved in the development process and what will their roles be? There should be a clear chain of command so decisions can be made quickly and by the appropriate person. A Work Group and/or Project Coordinator should be appointed with one person (preferably the Coordinator) serving as liaison and facilitator between the user agency and the developer. Higher levels of management may be less familiar with the day to day operations of the agency and may therefore have different viewpoints to provide about the application. Frequently, they are interested in the software as a tool for aggregate reporting and program planning. Be aware that the presence of higher level staff may inhibit the remarks of subordinates. It is important to pull together a small team with the minimum potential for personality conflicts. "Small" is a key word here as development time seems to increase proportionate with the number of people involved. Above all, make sure that the project team is well represented by individuals who will be using the software once it is completed.

c) Encourage "Blue Sky" Thinking: Consider and entertain all of the features and "bells and whistles" that the group comes up with. As the project progresses, technical and operational feasibility constraints will eliminate many of the requests. However, at this point everyone should be encouraged to express their vision of an ideal system.

d) Focus on the Problem to be Solved: While it may be exciting to imagine all the things that a computerized system could do for you, don't lose sight of the primary purpose of the software. Addressing the following questions may be helpful:

- What are the goals of the software? Keep these as concrete as possible. Make a list.
- How does your agency currently work? It is often useful for the developer to spend time at the agency site "looking over shoulders" and getting a feel for the agency work flow and an understanding of the day to day operations of the agency.

- What things do you need to count or track? Determine what is important about these things and how they are related to one another.
- What must the system produce? Envision exactly how you would like the written output to look and what information it should contain.
- Is this really necessary? Apply this acid test to every data element, report, and feature. If you can not operationally justify something, it probably doesn't need to be in your system. (Note: "It would be nice to have..." and "Maybe we might need it someday..." are not strong justifications.)

e) Work Backwards: By envisioning the end products of the software, one can then get a good sense of what the software must do and what it must contain in order to produce those products. Focus upon existing internal and external statistical reporting requirements, resource specific information that will be mailed to callers/consumers, aggregate data that may be of interest to program planners, and the formats in which the above should be presented. Producing hand made mock-ups of the printed report formats allows the developer to "work backwards" and ensure that the system is structured in such a manner that these reports can be produced. For example, the report mock-up in Table 2 indicates to the developer that a method for monitoring the utilization of predefined search procedures will have to be integrated into the system. The report additionally specifies the data elements to be stored and tracked and indicates which elements (region, program type, service) will require taxonomies.

Table 2: Report Mock-up

Computer Searches Done for the Period 03/05/90 to 03/07/90

User	*Search Criteria*			
	Number Found	*Region*	*Program Type*	*Service code*
03/05/90				
Robin	*16*	Northeast	Social/Leisure	
John	*12*	Greater Boston		K2
John	33			N5
Total Searches for Date:	**3**			
03/06/90				
George	*10*	Central	Early Intervention	
George	*0*	Greater Boston	Communication	B5
Robin	*42*	Boston	Support Groups	
John	*37*	West	Mental Health	
Total Searches for Date:	**4**			
Total Searches for Period: 7				

f) Determine Search Criteria and Taxonomies: Search criteria are the data elements that are used to locate program and resource specific information within the system. They are applied most frequently during predefined search procedures, in which the user keys into the system the criteria that the system will employ to locate data. It is advisable to choose the search criteria based upon the agency staff's day-to-day operations. The existing agency operations are usually consumer driven and reflect how callers typically request information. In most cases, a computerized I&R system will need to locate a resource or program by what it does (service), what it is (program type), where it is (location), and who it serves (population/disability).

Taxonomies allow the data about resources and programs to be classified in a consistent and meaningful manner. Within I&R systems they are often used to organize the data elements that will be used as search criteria. They are also valuable in ensuring consistent and unambiguous data entry. Evaluate any taxonomy currently in use by your agency and determine if it lends itself to automation. It seems a fact of life that no taxonomy is ever "complete", therefore attempt to keep it simple as it will surely grow. The software should allow users to add taxonomy items as needed.

2) User Requirements Definition

All of the work done in the planning/analysis stage gets documented by the developer in the User Requirements Definition. This document states in detail what the software should contain and is used as a basic system development "blueprint". It may be considered as an interim contract between the users and developer of the system. Included within it are descriptions of system goals and objectives, data-entry forms, taxonomies, reports and outputs, system maintenance procedures, and the hardware and software that will be used.

It is essential that the document be as free of technical jargon as possible. No assumptions should be made as to mutual meaning of commonly used words, phrases or expressions. For example, terms such as "program","client", "field" and "application" may hold entirely different meanings for the user and the developer.

When completed, the requirements definition should serve as a vehicle for all involved parties to pause and assess how the project is proceeding. Before continuing, the agency should determine if it has adequately educated the

developer regarding itself, its procedures, the needs of its staff and its consumers. Has it clearly and concisely conveyed what the system must do for them? Conversely, the developer needs to have begun a process of grounding the agency in the reality of what a computerized I&R system can actually provide. Are the users still up in the blue sky ambitiously envisioning a system that will intuitively provide them with a cornucopia of information while at the same time balancing their checkbooks? Careful attention to these issues at this stage will avoid wasted time and resources later in the project.

The user requirements definition, once it is reviewed and approved by all parties, details what the software should do. The prototyping stage shifts the focus over to how this will be accomplished.

3) The Prototyping Stage:

Rapid prototyping should be considered a necessity, not a luxury. Rarely does the initial version of a software capture all of the necessary features. The Database Management System (DBMS) used to develop the software applications needs to allow for fast design modifications. The cost of development is ultimately proportional to the difficulty in making changes. Given equal periods of time, fast and flexible DBMS development environments (DataEase, Paradox) will nearly always produce more full-featured systems than more labor intensive environments (C, BASIC, dBASE). Consider this: if Mr. Smith cuts his lawn with a pair of hand clippers, and his neighbor Mr. Johnson cuts his equally sized lawn with a riding power mower, which of the two do you think is going to have the time and energy to trim the hedges and perhaps do some creative landscaping?

Prototypes demonstrate that the information presented on a computer screen is indeed worth several thousand words. Using what has been agreed upon in the requirements definition (i.e. forms, tables, data elements, relationships) the developer begins to create a small prototype of the system. It is then shown to the user in order to present an initial look at how the theory of the requirements definition translates into a user/system interface. It is not necessary in this first prototype for all the "wires" to be connected nor all the features of the system to be in place. Rather, it's purpose is to begin a back and forth process whereby user and developer critique/modify in an interactive manner. The result of this process is the development of a system that has involved the user at every step. By giving users the opportunity to actually sit at the keyboard and "test drive" the system to provide feedback to the developer, the possibility of misconception regarding what is expected and what will be produced is

minimized. Each succeeding prototype brings the system closer to completion and, once this back and forth process is concluded, the developer needs only to integrate the components and add the "bells and whistles" necessary to perfect the system. The time it takes to arrive at an installable product is lessened and, when implemented, those users who participated in the prototyping process have an understanding of how the system works as well as a solid training base upon which to build and share with other users.

4) Implementation:

Consideration should be given to how the computerized I&R system is introduced into the procedural work flow of the agency. If there are several discrete system components, the agency may wish to implement them one at a time. If the system is to be implemented at several sites, the agency may choose to pilot it at a selected site. It is always wise to implement the system in parallel with any existing manual systems. This strategy is worth the extra expense of supporting two systems for a period of time because it minimizes damages in case the computerized system performs incorrectly.

Staff Training: Staff training may be provided at different levels and in different ways depending upon the size and organization of an agency. Here are some recommendations. At least one staff member within the user agency should be designated (see section on Work Group) as coordinator/liaison between developer and agency to facilitate automation/training. Having been intensively involved in the development process and the testing of prototypes, this person is already on their way to being the in-house "guru" and should be trained directly by the developer in areas of system utilization and maintenance. Middle managers should be trained next. They are the group that will need both of the types of information that an I&R system can provide: detailed service-specific information for clients/consumers, and aggregate information for use in program evaluation and planning. Once middle managers become aware of the usefulness of this new tool, they will see that their staffs learn what is necessary to take advantage of it.

The second level is the initial training of the staff who will routinely use the system. This training is done by the developer and instructs staff in how the parameters of the system, operational procedures and the underlying design philosophy. Understanding and acceptance of the system is improved if users have been previously involved in the work group, the prototyping stage or some other part of the development process. Training sessions should

include open discussion, allowing staff to present their questions and get answers, and should incorporate examples of the actual tasks that the staff will perform on the system. The coordinator should be present at this training to provide backup and to determine which areas, based on staff questions, should be focused upon in future sessions. After the initial training, staff should be encouraged to practice or "play" with the system before it is officially implemented. This will allow them to become more comfortable with the system in a less pressurized manner.

Most developers provide free support for a period of time following system implementation. This allows for training of both new staff and those who wish to enhance their computer skills, and allows the developer to fine tune the product and further evaluate its usefulness and effectiveness.

The User Manual: Many software development companies have user manual teams that work in parallel with the software development team. Most human service agencies don't have the resources to do this, however the production of a user manual should not be an afterthought to the software. It can be a resource saver down the road when new staff come on board. It is recommended that a user manual be conceptualized by developer and users jointly, but that an independent technical writer be responsible for the development of the finished product. A technical writer brings an impartial and objective perspective to this important process. This individual can also be used as an informal test of the system. The manual must be easily understood, so computer jargon should be avoided. Simple, instructive diagrams such as flow charts are useful. A Quick Reference card is extremely helpful for doing searches. It is helpful if what a user is supposed to be seeing on the computer screen is represented in the manual at appropriate points.

Conclusions: Putting it all into Perspective

While this discussion has focused upon the development of customized software for an Information and Referral system, the overall issues to be considered and the sequence of steps to be taken as addressed in this paper could apply to any number of projects. The planning and analysis are valuable even if an agency does not envision that it will be contracting with a software developer. If an agency has decided to contract with a developer to modify an existing system or build a new one, the development of an effective partnership between the parties is important. Of greater importance, however, is the involvement of the eventual users of the software in every step of the development process.

Developing and implementing an automated Information and Referral system can be a resource intensive undertaking. When completed you will hopefully have a useful technical tool that will assist in many of the functions of an I&R agency. But remember, it is just a tool. Make it serve you. Hold no reverence towards it when it works well, and no respect for it when it doesn't.

The software does not identify potential resources for inclusion into the database. It does not do the follow-up phone calls during data acquisition, nor does it enter the information into the computer. The software does not provide a caring and sensitive intermediary link between the information and the people who need it. It does not keep the information accurate and up to date. And finally, it does not raise public awareness about the availability of the information. As an agency involved in I&R, it is important to realize that while the investments in technology can be large, they should be considered start-up costs. The more important ongoing costs to be considered are those that support your most valuable assets: the people who drive the system.

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INFORMATION KALEIDOSCOPE:

ACHIEVING CONSENT: DELAWARE'S INTEGRATED SERVICE INFORMATION SYSTEM

Presented by:

Roseanne Griff-Cabelli, B.A.
Administrator
Coordinating Council for Children with Disabilities
Wilmington, DE

TO BE GIVEN TO PARENT/GUARDIAN (with ISIS Brochure) WHEN CONSENT FORM IS SIGNED.

THE DELAWARE INTEGRATED SERVICE INFORMATION SYSTEM (ISIS) is a computerized statewide tracking system for children at risk. "At-risk" children are children from newborn to eight years old whose parents or doctors are concerned about their growth and development. Private doctors, hospitals, and agencies are working together to make ISIS work for you.

THE PURPOSE OF ISIS IS:

- to better plan services for children
- to coordinate services to babies and young children
- to work toward having services available for children as early in life as possible. Some of these services are: audiology, speech/language, nursing, nutrition, occupational therapy (OT), physical therapy (PT), psychological, social work, special instruction in school.

ISIS WILL HELP CHILDREN AND THEIR FAMILIES BY:

- helping families who receive many services understand what they are getting
- helping families when children change from one program to another
- making sure all your information about services received is available to you whenever you want it
- helping to avoid duplication of services
- helping professionals to help families find services for their children and themselves.

THE ONLY INDIVIDUALS/AGENCIES ALLOWED TO LOOK AT THE INFORMATION are listed on the front of the Consent for Release of Information form you signed. You may add others, or refuse permission to any one of the listed agencies. Only those agencies or individuals who are providing services to your child and your family would have a need or interest in viewing your information.

THE KIND OF INFORMATION STORED IN THE ISIS SYSTEM is information that makes it possible to keep track of the services your child and family receives. Some examples are: name, address, phone, risks for developmental delay, medical diagnosis, plan of service, referrals. Information from private, confidential conversations you may have with any individual working with you and your family will not be entered into this computer.

YOU MAY ASK WHICH INDIVIDUALS OR AGENCIES ARE LOOKING AT INFORMATION ABOUT YOUR CHILD AT ANY TIME. You have the right to change that list whenever you want to.

ISIS CONSENT, SECURITY AND PRIVACY PROCEDURES

Confidentiality is a moral as well as a legal issue. In many states laws have been enacted to mandate registry of all children identified with birth defects. The ISIS Steering Committee feels that, although the process may be more cumbersome, it is vital that participation by families be the result of informed consent.

Assuring the confidentiality of service records for each patient/client and their families is crucial to the ability to obtain consent for participation in ISIS. Any possible fear by families that by participating in a computerized monitoring and tracking system their child may become "labeled" with a diagnosis that would limit future educational or occupational opportunities, will certainly be minimized by the benefits gained from participating in ISIS.

CONSENT

"Consent" means that -

1. The parent has been fully informed of all information relevant to the activity for which consent is sought, in the parent's native language or other mode of communication;
2. The parent understands and agrees in writing to the carrying out of the activity for which consent is sought, and the consent describes that activity and lists the information (if any) that will be released and to whom; and
3. The parent understands that the granting of consent is voluntary on the part of the parent and may be revoked at any time.

Procedure

1. All families receiving services from a participating ISIS member will be asked to complete a Consent for Release of Information Form no later than entry into the first referred program.
2. Only trained staff members will be assigned to present the ISIS system to parents to obtain consent.
   examples of appropriate staff:
   - case manager
   - program coordinator
   - social worker
   - Public Health nurse
   - schools: nurses
     special education coordinator
     Child Find specialist

PRIVACY

In order to insure the privacy of the individual child and his/her family:

1. Identifiable information may be shared only where there is a signed Consent Form on file with the Coordinating Council.
2. Any employee having access to the ISIS system will be required to sign a "Confidentiality Statement."
3. Data regarding non-participating families will be available only in aggregate form, and will not be individually identifiable.
4. All ISIS participant data will be available to parent/guardian at any time upon request.
5. At any time parent/guardian may add (or delete) agencies or individual practitioners to receive shared information.

CHECKLIST

( ) **THE DELAWARE INTEGRATED SERVICE INFORMATION SYSTEM (ISIS)** is a computerized statewide tracking system for children at risk. "At-risk" children are children from newborn to eight years old whose parents or doctors are concerned about their growth and development. Private doctors, hospitals, and agencies are working together to make ISIS work for you.

( ) **THE PURPOSE OF ISIS IS** to better plan services for children; to coordinate services to babies and young children; to work toward having services available for children as early in life as possible. Some of these services are: audiology, speech/language, nursing, nutrition, occupational therapy (OT), physical therapy (PT), psychological, social work, special instruction in school.

( ) **ISIS WILL HELP CHILDREN AND THEIR FAMILIES** by helping families who receive many services understand what they are getting; helping families when children change from one program to another; by making sure all your information about services received is available to you at any time; by helping to avoid duplication of services; by helping professionals to help families find services for their children and themselves.

( ) **THE ONLY INDIVIDUALS AGENCIES WHO WILL BE ALLOWED TO LOOK AT THE INFORMATION** are those listed on the front of the Consent for Release of Information form you signed. You may add others, or refuse permission to any one of the listed agencies. Only those agencies or individuals who are providing services to your child and your family would have a need or interest in viewing your information.

( ) **THE KIND OF INFORMATION THAT WILL BE ENTERED INTO THE ISIS SYSTEM** will be information that makes it possible to keep track of the services your child and family receives, for example: name, address, phone, risks for developmental delay, medical diagnosis, plan of service, referrals. Information from private, confidential conversations you may have with any individual working with you and your family will not be part of this computer information.

( ) **YOU MAY ASK AT ANY TIME WHICH INDIVIDUALS OR AGENCIES ARE LOOKING AT INFORMATION ABOUT YOUR CHILD** and you have the right to change the list of those able to share information about your child at any time.

****

( ) I NEED TO KNOW THAT I HAVE EXPLAINED THIS PROGRAM TO YOU CLEARLY, AND THAT YOU UNDERSTAND IT, so would you please tell me:

( ) How do you think ISIS works? (let him/her explain in his/her own words - without prompting).

( ) What benefits do you expect to get from participating in ISIS?

( ) HAVE YOU MADE SURE THE PARENT UNDERSTANDS EVERYTHING YOU HAVE SAID?

_____

Signature of Agency Individual Obtaining Consent to Participate in ISIS

PLEASE ASK PARENTS

Yes	No	
[ ]	[ ]	I would like to be part of a state-wide parent-to-parent network for support and sharing of information. Therefore please release my name and address to the Parent Information Center of DE., Inc.

February 1, 1992 Vol. I, Number 3

CCCD COORDINATED ACTION

A Newsletter
Published by the
Coordinating Council for Children with DisAbilities

Committee Resolves Confidentiality Catch 22

When a project like ISIS (Integrated Service Information System) comes along which is designed to help children who are experiencing or at risk of developmental delay or disability, and the project needs hospitals, private physicians, and public and private agencies to share information and put it into a computer in order to benefit the child and any service provider, the right of confidentiality of a client, in this case the child, is a big issue.

Combine a nationwide tangle of federal and state programs designed to help people who need help, with physician's and attorney's codes of conduct, the consent forms of social services agencies, and hospitals and one has a quagmire of conflicting rights and needs which would seem almost impossible to resolve.

Hence, a hard working committee has worked closely with the deputy attorney general's office for two different departments, Health and Human Services, the Department of Public Instruction, parents, the advise and consent committees, attorneys representing The Medical Center of Delaware, and more. The committee, led by Dr. Doug Spencer, Bruce Orr, Nancy Colley, and Marjorie Van Gulick, has been successful in developing a prototype of forms and policies in order to allow all those involved with ISIS to do interagency sharing when necessary to benefit the client. For Delaware ISIS, the patient's right to confidentiality and service providers' need to know issue has been resolved in a way which will benefit all. This is quite an accomplishment. Delaware ISIS was cited several times in the recent document "Coping with Confidentiality: Information sharing in Interagency Efforts" a joint publication of Joining Forces, Council of Chief State School Officers, American Public Welfare Association, Center on Law and Social Policy and Education Commission of the States.

Building on that work for ISIS is the confidentiality committee of Delaware Interagency Council for Children & Families which also needs to include guidelines for sharing information and obtaining and using data for purposes of research, long range planning and program evaluation. Members of that committee are Rosanne Griff-Cabelli, Cliff Hutton, Joan Powell, Martha Brooks, Chris Long, Carol Sipe, Roberta Ray and David White.

Drs. Rivera And Craven To Join CCCD Board

Dr. Jaime Rivera will be elected to the CCCD board and will begin a three year term in February, 1992. Dr. Rivera is a practicing pediatric gastroenterogist and nutritionist and has long been interested in the enhancement of life for children with disabilities.

Dr. Elizabeth M. Craven, pediatric consultant for Division of Public Health, and Medical Center of Delaware, and a practicing physician with a specialty in pediatric pulmonary and cystic fibrosis problems, will also join the CCCD board member beginning in February, 1992. Dr. Craven is an advocate for improved patient care in Delaware.

Greetings From The CCCD Chair

Honorable Jane Maroney

It has been very gratifying to initiate the concept of ISIS during my three years as chairman and to shepherd it through the design and implementation phase. Monies are currently being sought for Phase II of the tracking process, which should be completed within the next twelve months.

The example set by Delaware's public and private agencies, hospitals, and physicians, collaborating on behalf of their patients and clients, demonstrates a spirit of true public/private partnership at work. I believe this example will set the pace for more coalitions to come as communities plan for the future.

Thank you all for your support during my tenure, especially members of the executive committee of the Coordinating Council, leaders in and out of government, and to our administrator, Rosanne Griff-Cabelli, for her tenacity in marshalling the forces needed to see a vision brought to fruition. I remain committed to helping children and their families here in Delaware and around the nation to prosper and to help them realize their full potential as healthy, productive members of their communities.

Legal Guardian _____
Address _____
_____
Soc. Sec. No.: _____
Sex: _____
Race: _____
Date of Birth: _____

Child's Name: _____
Soc. Sec. No.: _____
ISIS ID No.: _____
Sex: _____
Race: _____
Date of Birth: _____

DELAWARE I S I S
INTEGRATED SERVICE INFORMATION SYSTEM

Consent for Release of Information

The Integrated Service Information System (ISIS) is a state-wide tracking and monitoring system that involves private physicians, hospitals, public agencies and private agencies cooperating together to help your child receive services. This project has wide public and private support, and was established by a Delaware legislative resolution of the 135th General Assembly, Senate Concurrent Resolution #91 (SRC #91).

This Integrated Service Information System has been explained to me, I understand it, and I, _____, (Parent/Guardian) hereby consent to my child, _____ being included in the Integrated Service Information System for tracking and monitoring purposes. This consent is valid for eight years from date of signature. I understand that information regarding my child may be shared among the organizations and/or individuals listed below, and I also consent to release of information pertinent to my child to and from all authorized ISIS participants only, **EXCEPT** the following:

_____

_____

_____

I understand that further disclosure is prohibited without signed release. I understand I may review/revise/revoke this list at any time.

Witness: _____

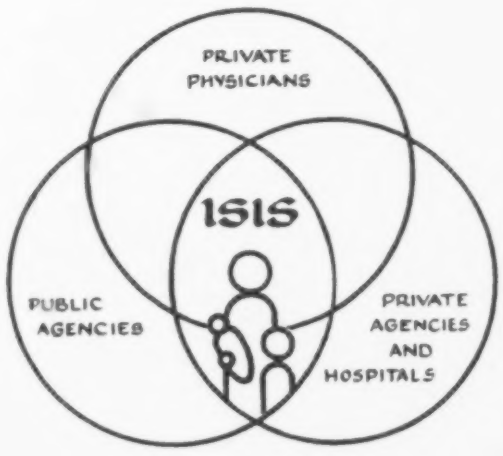
Signature _____
Parent/Guardian

Date _____

****

Participating Organizations:

Alfred I. duPont Institute
Beebe Medical Center
Coordinating Council for Children with DisAbilities
Delaware Curative Workshop
Department of Health/Social Services
Department of Public Instruction
Local School Districts
Easter Seal Society of Delmar
Kent General Hospital
Medical Center of Delaware
St. Francis Hospital
Private Physicians: _____
_____
Other: _____
_____



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WHITE: AGENCY YELLOW: LEGAL GUARDIAN PINK: COORDINATING COUNCIL

Note: If the parent/guardian does not understand the content because he/she is not fluent in English, the information must be translated and the translator must sign the affidavit.

TRANSLATOR'S STATEMENT

I have verbally translated the above into _____ (language) for benefit of the parent/guardian, who better understands this language than English. To the best of my ability, I believe the parent/guardian understands the statements, as witnessed by his/her signature. I understand that any false statement made by me will be considered perjury, and result in action by ISIS Management.

DATE_____ TRANSLATOR'S SIGNATURE _____

REFUSAL TO PARTICIPATE

I refuse to consent to my child being included in the Integrated Service Information System for tracking and monitoring purposes. I understand that my refusal will in no way be held against me, nor will my refusal be cause for withholding of services for my child.

DATE _____ Parent/Legal Guardian _____

Witness Signature _____

PROCEDIMIENTOS DE SEGURIDAD Y PRIVACIDAD CON ISIS
(El Sistema Integrado de Informacion)

La confidencialidad es un principio no solo moral, sino legal. En muchos estados de los (EEUU) Estados Unidos existen leyes implementadas que obligan el registro de niños identificados con defectos de nacimientos. El Comité Dirigente de ISIS (El Sistema Integrado de Información) cree que aunque el proceso sea un poco engorroso, es fundamental que la participación de las familias sea obtenido con su consentimiento y conocimiento.

El paciente o cliente y su familia deben de estar seguros que su registro (expediente) de servicios estan protegidos en confidencia total, antes de dar su permiso para participar en el registro ISIS. Cualquier temor que expresen las familias por razón de ser incluídas en el sistema ISIS, o sea, una diagnosis que pueda limitar en un futuro las posibilidades educacionales o de empleamiento, sera complementada por aquellos beneficios que puedan recibir al ser incluidos en el sistema ISIS.

CONSENTIMIENTO (PERMISO)

"Consentimiento" quire decir que -

1. Las padres han sido informados de todos las detalles sobre cual el consentimiento es acechado; y aquellos que buscan el permiso le han comunicado dicho informe en su propio idioma u otros medios de comunicacion.
2. Los padres comprenden y acceden por escrito a cumplir con esas actividades por la cual el consentimiento se ha dado. Tal consentimiento describe aquellas actividades e informaciones (si es aplicable) que sera compartida y a quien se le divulgara tal inmformacion sobre el cliente o paciente.
3. Los padres entienden que dan este consentimiento voluntariamente y puede ser revodado en cualquier momento.

PROCEDIMIENTOS

1. Todas las familias que reciben servicios de un miembro de ISIS les será solicitado que llenen el documento Consentimiento Para Compartir Información (Consent for Release of Information Form) al entrar en el primer programa.
2. Solamente aquellos empleados especialmente entrenados serán seleccionados para presentar el sistema ISIS y obtener el consentimiento o permiso. Unos ejemplos de empleados apropiados son:

   Gerentes de casos
   Direngentes de diversos programas
   Trabajadores Sociales
   Enfermeras de Sanidad Publica

   En las escuelas:
   Las Enfermeras
   Coordinadores de educacion especializada
   Especialistas de "Child Find"

DERECHO DE PRIVACIDAD

Para asegurar que cada niño y su familia reciba la mayor privacidad, ciertos procedimientos son implementados:

1. Informacion que identifique al recipiente de los servicios sera dado solamente cuando exista el "Documentto de Consentimiento", firmado y registrado con el Consejo Coordinador.
2. Toda empleado con acceso al sistema ISIS tendrá que firmar la "Afirmación de Confidencialidad".
3. Datos pertenecientes a familias que no participen en ISIS, sera disponible solamente en forma agregada y no podran ser identificados individualmente.
4. Todos los datos acumulados en el sistema ISIS estarán a la disposición de los padres o guardian legal en cualquier momento que deseen revisarlo.
5. Los padres o guardianes legales puedan anadir o borrar a cualquuier agencia o individuo que tenga el derecho de revisar informe contenido en ISIS.

LISTA DE CONTROL

( ) **EL SISTEMA DE INFORMACIÓN DE SERVICIOS INTEGRADOS** en el estado de Delaware es un sistema de registro computarizado que inscribe a aquellos ninos que corren riesgo de algun padecimiiento. Estos ninos de recien nacidos hasta la edad de ocho años, que son identificados bien por sus padres o personal medico, como sufriendo con problemas de desarrollo o crecimiento normal, son catalogados "ninos en riesgo". Diversas agencias, hospitales y medicos privados estan laborando a su favor para que el sistema ISIS le beneficie.

( ) **EL PROPOSITO DE ISIS** es mejorar el plan de servicios para los ninos; la meta es ofrecerle a los niños servicios lo antes posible en su vida. Por ejemplo, algunos de estos servicios includos son: audiologia, terapia linguistica, enfermeria, nutricion, terapia ocupacional, terapia fisica, servicios psicologicos y sociales, al igual que instrucción especializada en las escuelas.

( ) **ISIS ASISTE A LOS NIÑOS Y A SUS FAMILIAS** de manera que ellos, comprenden los servicios que estan recibiendo y el porque a vaces hay cambio en aquellos servicios ofrecidos. ISIS les asegura informarles de todos los servicios a su alcanze; les garantiza que no exista duplicación en tales servicios. Finalmente los profesionales pueden ayudarle a encontrar la mejor asistencia para su nino y su familia.

( ) **LOS UNICOS INDIVIDUOS CON DERECHO A VER SU EXPEDIENTE** son aquellas agencias o individuos nombrados al frente de el documento llamado "Consent for Release of Information" (Documento que autoriza divulgar informacion sobre su familia). Usted puede agregar otras personas o agencias y tambien prohibir que su informe sea compartido por diversas personas o agencias. Solamente aquellas agencias o individuos que les prestan servicios a ud. y los suyos tendran necesidad o interes en ver su expediente.

( ) **El tipo de informacion que sera registrado en el sistema de ISIS** es aquel informe perteneciente a los servicios que su nino y su familia recibe, por ejemplo:

A. nombre, direccion, y telefono
B. padecimiento o diagnostico de retrazo del desarrollo
C. diagnostico medico
D. plan de servicio(s) prestados al paciente
E. referencia(s) ofrecidas o dadas a otros servicios

Conversaciones privadas o confidenciales que ud. tiene con individuos que trabajan con ud. o su familia no seran incluidas en su expediente computarizado.

( ) **Usted puede preguntar en cualquier momento quien tiene acceso a su expediente** y tambien ud. tiene el derecho a cambiar o excluir a personas en la lista.

****

( ) **YO NECESITO SABER SI YO LE HE EXPLICADO ESTE PROGRAMA CLARAMENTE, Y UD. LO COMPRENDE,** asi que por favor respondame:

( ) En sus propias palabras, como cree ud. que trabaja el sistema de ISIS?

( ) Que beneficios espera ud. recibir al participar en ISIS?

HAVE YOU MADE SURE THE PARENT UNDERSTANDS EVERYTHING YOU HAVE SAID?

Firma del personal que obtuvo el consentimiento de ISIS (Traductor)

Pregunta para los padres:
( ) SI ( ) NO Me interesa ser miembro del grupo "de padres-a-padres" que ofrece apoyo e informacion a personas en circumstancias similares a las mias. Afirmo que doy permiso para que Parent Information Center de Delaware, Inc. reciba mi nombre y direccion.

Guardian legal_____ Nombre del Niño_____
Direccion_____ No. de Seguro Social_____
No. de Seguro Social_____ No. de ISIS_____
Sexo_____ Sexo_____
Raza_____ Raza_____
Fecha de Nacimiento_____ Fecha de Nacimiento_____

DELAWARE ISIS
SISTEMA DE INFORMACION DE SERVICIOS INTEGRADOS

CONSENTIMIENTO PARA DIVULGAR INFORMACION

El sistema ISIS es un registro computarizado para trazar y vigilar los servicios que recibe su hijo que incluye hospitales, medicos privados, agencias publicas y privadas.Estos agentes profesionales cooperan en ayudar a su hijo a recibir servicios. Este proyecto tiene el respaldo privado y publico, y fue establezido por la Legislatura del estado de Delaware de la 135 Asamblea General, Resulucion#91 del Senado(SRC#91).

Este Sistema Integrado de Informacion (ISIS) a sido explicado a mi persona, y yo _____ lo comprendo, y accedo a que mi hijo,_____ sea incluido en el sistema ISIS con el proposito de mantener vigilancia y trayecto de servicios. Este consentimiento tiene ocho años de vigencia a partir de cuado yo firme. Yo entiendo que la información perteciente a mi hijo sera compartida con las organizaciones e individuos nombrados en este documento, y tambien doy permiso para que los miembros autorizados de ISIS compartan información acerca de mi hijo con **EXCEPCIÓN DE**_____
_____

Yo estoy consiente de que todo informe fuera de lo que este documento garantiza no puede ser divulgado sin mi permiso. Yo comprendo que yo tengo el derecho a revisar, revocar o cambiar esta lista cuando lo desee.

Testigo_____

Firma_____ _____
Padre(s)/ Guardian Legal
Fecha_____
****

Organizaciones Participantes:

Alfred I. DuPont Institute
Beebe Medical Center
Coordinating Council for
Children with Disabilities
Delaware Curative Workshop
Department of Health/Social Services
Department of Public Instruction
Local School Districts
Easter Seal Society of Delmar
Kent General Hospital
Medical Center of Delaware
St. Francis Hospital
Medicos Privados: _____
_____
_____
Otros:_____
_____
_____

INFORMATION KALEIDOSCOPE:

BEYOND INFORMATION AND REFERRAL: ARE THERE OTHER BENEFITS TO HAVING A STATEWIDE INFORMATION AND REFERRAL SYSTEM?

Presented by:

Melinda Grubbs
Assistant Project Director
Center for Developmental Disabilities
University of South Carolina
Columbia, SC

BEYOND INFORMATION & REFERRAL

Are There Other Benefits to Having a Statewide Information & Referral System?

Melinda H. Grubbs
SC Services Information System (SCSIS)
7th National Symposium on Information Technology
May 1992

The primary goal of an information & referral system is to connect persons needing services to those services.

ADDITIONAL BENEFITS TO INDIVIDUAL CITIZENS

A statewide I&R system:

1. Makes "negotiation" of the human service delivery system smoother by providing information about **accessing** services as well as providing contact names and numbers.

2. Can "feed" into a statewide Service Coordination System which crosses over agency lines to ensure service delivery, such as, Hawaii's Zero-to-Three Project.

3. Assists persons not eligible for Service Coordination from an agency with the coordination of services from multiple providers.

4. Can act as a "central point of entry" to multiple state agencies. Some states use their statewide I&R system to get into "the System", all state agencies.

5. Can have significant financial and "quality of life" impact on individuals. (i.e., see example to follow)

ADDITIONAL BENEFITS TO THE STATE SYSTEM AND PROVIDERS

A statewide I&R system:

1. Can identify "gaps" in services throughout the state.

2. Can identify "duplication" of services throughout the state. Both 1 and 2 can save the State money by directing funds to where there are needs.

3. Can assist state planners in setting up new programs, such as those required by PL 99-457. SC has played a significant role in providing the lead agency for Part H with the required services which are available in each county. Funds and efforts have been used to "fill in the gaps".

4. Can assist in identifying "hot spots" of conditions in the state. (Research purposes, etc. Is there a prevalence of Spina Bifida, Down Syndrome, etc. in certain areas of the state? Should research be done to investigate this?)

5. Can assist professionals in the field to locate subjects for surveys and research. SC's System will not provide callers' names and numbers, but will contact callers who have particular conditions, etc. and offer them the opportunity to participate by giving contact information of the professional doing the research and at times providing the survey instrument to the callers.

6. Can let a large number of interested people know about meetings, conferences, legislation pending, etc. When the Zebley ruling came down about reviewing cases of children denied SSI in the past, SC's system make a particular effort to inform callers about this ruling. One of the first cases to get back payments due to this ruling was in SC.

7. Can participate in Outreach programs. SC recently participated in an SSI Outreach project acting as a point of contact to direct targeted persons to local agencies which would help in the filing of SSI applications. A significant side benefit was that we were able to direct a lot of additional callers who were not in the targeted areas (and therefore, did not receive the mailing) about the possibility of receiving SSI and direct them to their local Social Security office to apply.

7. May act as a receiver of opinion surveys about issues impacting the target population(s). SC has taken part in an opinion survey about needs of children, age 0-3, with special needs and their families by allowing our toll-free number to be on the opinion survey to call in opinions. It was determined that more people will call a free number than will respond in writing.

8. Can save significant amount of money for the state. Many separate state agencies are required to provide or assure that I&R is available. Multiple budgets, staffs, and systems do not have to be operated.

9. Can identify unique programs for the purpose of modeling others after it. Can identify "experts" in the field. Since 1985, a little known project, a Mobile Classroom for mothers and children, has been in use in the Low Country area of SC. This is a concept many people are discussing now for many uses. The project staff could be a valuable asset in setting up similar programs.

10. Can assist in system changes through identifying needs, problems, etc.

    a. SC noted through data collection that only one Home Health agency in the state provides home health service to technology dependent children. The SC Home Health Association has taken up the task of attempting to educate and solicit providers to offer this service to this population.

    b. Keep statistics on persons complaining about a particular issue relevant to the target population(s). SC's system had noted and passed along complaints about abuse of parking for the handicapped to appropriate state agency, legislators, etc. Legislation is pending in SC to allow store, mall personnel to tickets cars illegally parked in designated spaces. Fine was raised several years ago.

    c. Identify unmet needs and direct to appropriate agencies, persons. Offer solutions. SC System has recently identified the need for financial assistance for prescription medication or provision of low cost or free medication to many Senior Citizens. We directed this need to the Federation of Older Americans who have taken significant steps in attempting a solution which we suggested, a Drug Depository. The concept is to have a Depository for prescriptions which are not

used up or caused a reaction, therefore, the person had to get a different drug. Senior Citizens could then tap into this depository for prescriptions at free or low cost. While this concept has many hurdles to jump, and the Depository may not be it, the Federation is determined that something will be done to alleviate this tremendous problem.

11. Can produce mailing labels of providers of human services.

Quality of Life Impact

Jessica's Story

In October 1988, a 16 year old female in a rural county in SC had a hemipelvectomy, a very high hip amputation, due to cancer. Since surgery, Jessica had been fitted with a prosthesis. The prosthesis was heavy, cumbersome, and painful. She was assured that this was all that was available.

After her refusal to wear the prosthesis, she and her mother became resigned to her using a wheelchair and being without the leg. Her mother called the South Carolina Services Information System hoping to find someone to share pairs of shoes with Jessica. In the course of the call, the mother relayed the information about the prosthesis. She explained that the amputation was so high that there just wasn't a prosthesis that worked very well. The Information Specialist was able to give the mother information about sharing her daughter's shoes through the Odd Shoe Exchange. The Information Specialist asked if she could do some research into the prosthesis and get back to her. The mother was agreeable.

Through a cooperative project with the Center for Rehabilitation Technology, the Information Specialist obtained information about a particular prosthesis developed in Tulsa, OK, which works well for high amputations. She called the company and was sent two video tapes showing persons using this type of prosthesis. The tapes were taken to the local hospital where the daughter was receiving chemotherapy. The daughter was feeling despondent about her situation and all that she felt she was going to "miss out on," like dancing, running, driving. After viewing the tapes, she had a new look on life as she began talking about "her leg." Her doctor viewed the tapes and was quite impressed. He showed them to other doctors at the hospital.

At this point, the Information Specialist began looking for funding sources for this family to be able to purchase the $10,000 prosthesis and fly to Tulsa and stay there while the prosthesis was made, fitted and she was trained. Medicaid would not pay for it and the family did not have the resources. A call to the Shriner's Hospital in Greenville, SC, resulted in an appointment for her. They make a prosthesis with the same features and success as the one from Tulsa and they would assume all financial responsibility for it!

At last report, Jessica was back in the swing of a typical teenager's life, driving a car, going dancing and being an inspiration to others she meets.

How can the impact of this be measured? All that have been involved with this success story feel that Jessica will become an adult with contributions to make to this community. Her mental state and her physical state have been improved dramatically. Financially, it is felt that Jessica can and will be employed and not dependent upon the government. Her health is improved with a more active lifestyle. Her dependence upon assistive technology will be reduced throughout her lifetime. All in all, the phone call to SCSIS made a difference for Jessica!

1992 PRESENTERS THAT DID NOT PROVIDE PAPERS FOR INCLUSION IN THE NSIT PROCEEDINGS

Information Kaleidoscope: **Accessing Disability Information Through Electronic Bulletin Boards**
John Alam

Information Kaleidoscope: **Americans With Disabilities Act: Effects on Information and Referral Programs**
Cherie Clark

*__Report of the Findings of the National Assistive Technology Information and Program Referral Network__
Ana De Fede

*Information Kaleidoscope: **Assessing the Needs of Underrepresented Consumers of Assistive Technology Information Services**
Lucy Trivelli

*The results of the National Assistive Technology Information and Referral Feasibility Study is the proprietary property of the National Institute on Disability and Rehabilitation Research (NIDRR), United States Department of Education. The final reports of the study will be released to the general public in the Fall of 1992. For a copy of the findings, you may contact:

Ms. Ana De Fede
Center for Developmental Disabilities
University of South Carolina
Benson Building, 1st Floor
Columbia, SC 29208
(803) 777-4435

Strategies for Development of Resources for Identification and Tracking of Children With Special Health Care Needs
Mary T. Olguin, Donald A. Paul, Russell S. Kirby, Melinda Pavin

Demonstration of the 21st Century Interactive Information Systems and Discussion of Accessibility Issues
Gregg C. Vanderheiden, Jackson Tung

The Use of Real-Time Searching During the Construction of a Database Search
Gregg C. Vanderheiden, Kelly Ford

Electronic Database Libraries: A 650-Megabyte Disability Library in Your Pocket
Gregg C. Vanderheiden, Kelly Ford

1992 EXHIBITORS

EXHIBITORS

Cerebral Palsy Research Foundation of Kansas
Chris Leslie
P.O. Box 8217
Wichita, KS 67208
(306) 688-5687)

Client Tracking Systems for Minnesotans with Developmental Disabilities
James Franczyk, Patti Harris
Minnesota Department of Human Services
Division for Persons with Developmental Disabilities
444 Lafayette Road
St. Paul, MN 55155
(612) 296-2171

District of Columbia Linkage and Tracking System
Martinez Box, Alison Baytop
DC General Hospital, Dept. of Pediatrics
4th Floor, West Wing, Room 401
1900 Massachusetts Avenue, Southeast
Washington, DC 20003
(202) 727-3866

Evaluation and Product Comparison of Assistive Devices
Brian Kemlage
REquest Rehabilitation Engineering Center
National Rehabilitation Hospital
102 Irving Street, Northwest
Washington, DC 20010
(202) 877-1932

Hyper-ABLEDATA and the Service Delivery Directory
Gregg Vanderheiden, Kelly Ford
Trace Research & Development Center
S-151 Waisman Center
1500 Highland Avenue
Madison, WI 53705
(608) 262-6966

Integrating Information & Referral with Client Tracking
Jacquelyn Vincson U'Deen, Edward Hamlin
Children's Support Systems
LaRabida Children's Hospital
950 East 61st Street
Chicago, IL 60637
(312) 324-9495

NARIC & ABLEDATA Information
Mark Odum, Amylynne Landers
MACRO International, Inc.
8455 Colesville Road, #935
Silver Spring, MD 20910
(800) 346-2742

National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions
Kathy Mayfield-Smith
Center for Developmental Disabilities
University of South Carolina
Benson Building, 1st Floor
Columbia, SC 29208
(803) 777-4435

National Information System for Vietnam Veterans and Their Families
Bryan Smith
Center for Developmental Disabilities
University of South Carolina
Benson Building, 1st Floor
Columbia, SC 29208
(803) 777-4435

New England INDEX
George Jones, Robert Bass
Shriver Center University Affiliated Program
200 Trapelo Road
Waltham, MA 02154
(617) 642-0286

PRISM - A Windows Information and Referral Software Package
Georgia Sales
INFO LINE of Los Angeles
3035 Tyler Avenue
El Monte, CA 91731
(818) 350-1841

Project Res-Tech: Generic Assistive Technology
Steven Tello
Seaside Associates, Inc.
P.O. Box 341
Lincoln Center, MA 01773
(617) 893 7990

RESNA
Lucy Trivelli
RESNA Technical Assistance Project
1101 Connecticut Avenue, Northwest
Suite 700
Washington, DC 20036
(202) 857-1140

San Diego Information System (SANDIS)
Alan Kaplan, Steven Kregness
San Diego-Imperial Counties Developmental Services
4355 Ruffin Road, #205
San Diego, CA 92123
(619) 576-2813

South Carolina Services Information System
Denise Wiles Rivers, Melinda Grubbs
Center for Developmental Disabilities
University of South Carolina
Benson Building, 1st Floor
Columbia, SC 29208
(803) 777-4435

South Carolina Assistive Technology Project
W.L. "Chip" Harriford
Department of Vocational Rehabilitation
P.O Box 15
West Columbia, SC 29171
(803) 822-5404